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## A qualitative investigation of the self-concept of older adults presenting with the symptoms of dementia

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**TRACY REED BSc HONS**

**A QUALITATIVE INVESTIGATION OF THE  
SELF-CONCEPT OF OLDER ADULTS PRESENTING  
WITH THE SYMPTOMS OF DEMENTIA.**

**A thesis submitted in partial fulfillment of the requirements of the Open  
University for the degree of Doctor of Clinical Psychology**

**OCTOBER 2000**

**SALOMONS  
CANTERBURY CHRIST CHURCH UNIVERSITY COLLEGE**

## DECLARATION

This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree.

Signed ..... T.B. Red. ..... (Candidate)

Date ..... 20.7.00 .....

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## **ACKNOWLEDGEMENTS**

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## **Abstract**

### **Objectives:**

Historically, a predominantly biomedical understanding of dementia developed. In contrast, research investigating the subjective experiences of people with dementia has been limited. The present study aimed to develop a greater understanding of whether older people recognise their symptoms of dementia, and their perception of the effect of dementia on relationships and activities. Furthermore, the impact of these on self-concept was investigated.

### **Design:**

The study employed a cross sectional qualitative research paradigm following the principles of Interpretative Phenomenological Analysis (IPA) and also drew upon Grounded Theory Methodology. The principles of content analysis were also employed to measure the participant's recognition of their symptoms of dementia.

### **Method:**

Ten participants, five male and five female were recruited through four NHS mental health services for older people. Participants were older adults, exhibiting the symptoms of dementia in the mild to moderate range of severity and who had been informed of a diagnosis e.g., memory problems. The Mini Mental State Examination was administered to assess dementia severity to establish inclusion criteria. The Geriatric Depression Scale-15 (GDS-15) was administered to assess the severity of depression. Face to face interviews were conducted using a semi-structured interview schedule to address the aims described above.

### **Results:**

Using content analysis it emerged that participants spontaneously mentioned their recognition of two or more symptoms of dementia and a further four or more when prompted. The rest of the interview data were analysed using IPA. Themes and categories were generated from the data and organised into three sections, 1) participants' reactions

to their symptoms of dementia 2) other's reactions to the participants' symptoms of dementia and the participants' counter responses and 3) participants' reactions to the loss of activities.

### Conclusions

Three tentative theoretical frameworks were developed from the participants' responses which correspond to the three sections above. The implications of these results for clinical practice were discussed with respect to individual and family work, working within organisations and service evaluation. Suggestions have also been made regarding future research.

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## **1. Introduction**

The author's interest in the subjective experiences of older people with dementia developed whilst undertaking a clinical placement for the Doctorate in Clinical Psychology. From the author's experiences it appeared that, in comparison to child and adult mental health services, the structure of services for older people continued to be largely led by the medical model of care. Interest and curiosity thus developed regarding the social and psychological needs of this population generally, but in particular of those people with dementia. For the latter group, several questions emerged regarding the subjective experiences of receiving a diagnosis of dementia, awareness of failing abilities and the impact of these on relationships, roles and the subsequent sense of self.

A literature search concerned with the subjective experiences of people with dementia produced surprisingly scant results. Similarly, Kitwood (1997) discovered that there was no mention of the subjective experiences of dementia in any of the major textbooks of Clinical Psychology or Psychiatry which had been published during the previous five years. Furthermore, it was the view of several authors that the literature available predominantly focussed on the biomedical aspects of dementia (e.g., Cottrell & Schulz, 1993). However, during the past decade an extensive literature base has also developed concerning caregiver burden and stress (e.g., Pearlin, Mullan, Semple & Skaff, 1990; Green, 1982).

The literature search revealed that a number of studies had been undertaken to investigate the subjective experiences of people with depression, schizophrenia and chronic illness. The findings from these studies were consulted when the potential impact of living with

dementia was considered. Charmaz (1983) found that one consequence of chronic illness was the disruption to the person's self-concept. It was hypothesised that dementia may have a similar effect. This prompted the following investigation, as a relationship exists between negative self-perceptions and low-self esteem, which has implications for clinical practice.

In this section, a review will be undertaken of the research literature and issues related to dementia and self-concept. The section will begin with a definition of dementia and an overview of the predominantly biomedical understanding of dementia. This will be followed by the research literature pertaining to chronic illness and its impact on the person's self-concept. To provide an understanding of how identity develops, is maintained and threatened, the social-psychological theories of self will be reviewed. In the latter part of this section hypotheses are proposed for the almost total exclusion of research literature investigating the subjective experiences of people with dementia, followed by a review of the limited studies that have been undertaken so far. The section concludes with a discussion of the utility of qualitative methodology, before setting out the rationale for the study, the aims and the research questions.

### **1.1. What is dementia? Medical definitions.**

The prevalence figures of dementia in people over the age of sixty-five in individual societies is between two and twenty percent (Kitwood, 1997a). In the UK alone, it was estimated that there were around 650,000 people with dementia (Alzheimer's Disease Society (ADS), 1995), half of whom were estimated to have Alzheimer's disease. The

prevalence figures increase with mild dementia from three to sixty-four percent (hart & Semple, 1990). One reason proposed for such variability in prevalence rates is the difficulty of accurately diagnosing dementia (Keady & Gilliard, 1997). This will be discussed in more detail later.

A medical definition of dementia provided in the ICD-10 Classification of Mental and Behavioural Disorders (World Health Organisation (WHO), 1992) is:

"....a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement.....Impairments of cognitive function are commonly accompanied and occasionally preceded by deterioration of emotional control, social behaviour or motivation." (p45).

This definition is all-inclusive and encompasses the various causes of dementia. Such broad definitions might render the diagnosis of dementia unreliable. Alternatively, Lawrence & Sahakian (1996) considered the most useful diagnostic criteria to be those developed by Cummings and Benson (1986). They proposed that a diagnosis of dementia requires the "sustained loss of at least three of the following; cognition, memory, visuospatial function, language and alterations in social behaviour" (p15). This is clearly a simplified definition and usefulness will depend upon its intended application.



There are various causes or types of dementia such as, Alzheimer's disease, vascular dementia, Lewy Bodies dementia and frontotemporal dementia. Each have different aetiologies, neuropathologies and clinical characteristics such as age of onset, duration of illness and rate of decline (Lawrence & Sahakian, 1996). Consequently, they produce differing presentations with respect to cognitive functioning, behavioural and speech disorders, affective symptoms and physical signs. Furthermore, there is variability within the categories of dementia such as Alzheimer's disease due to the heterogeneity of these conditions (Boller, Forette, Khachaturian, Panet & Christen, 1992). Reasons proposed for such heterogeneity is that Alzheimer's is a single disease process, producing differing responses, or an umbrella term, encompassing various pathological states (Kitwood, 1997a).

Dementia has been divided into three distinct stages within the DSM-IV (American Psychiatric Association (APA), 1994) and the ICD-10 (WHO, 1992), namely, mild, moderate and severe, although various means of rating the severity of dementia have been proposed (See Keady & Gilliard, 1997). It is not possible to detail and review the various assessment techniques and rating scales here.

## **1.2. Predominance of the Medical Model**

Cottrell and Schulz (1993) reported that historically a predominantly biomedical understanding of dementia developed. The biomedical approach has been criticised by a number of authors. Cottrell & Schulz, (1993) felt that the medical approach viewed those with dementia as a 'disease entity', an object that can be studied, as opposed to someone

who can legitimately contribute to our understanding. Furthermore, this approach is believed to have led to the fragmentation of the person into "interconnected but distinct parts, each the province of a specialist physician" (Dubos, 1965, cited in Goldsmith, 1996, p6). Both views suggested that the processes of objectification and fragmentation could undermine the person's sense of self. In response, Goldsmith (1996) strongly emphasised that there is more to people than their illness and felt that an overemphasis on the biomedical view "can rob us of appreciating the subtleties and complexities of a person in their personal and social context" (p7). Although it is clearly necessary to consider the potential impact of the medical approaches, it is important not to take a reactionary position and dismiss or negate their significant contributions to our understanding of dementia. As Kitwood & Bredin (1992) emphasised, it would be advantageous to combine a number of approaches to obtain a holistic picture of the person with dementia. They proposed that dementia should be "viewed as the outcome of a dialectical interplay between two tendencies; neurological impairment and the personal psychology an individual has accrued, together with the social psychology with which he or she is surrounded" (p 271).

### **1.3 The subjective experience of chronic illness**

As people with dementia have been provided with little opportunity to voice their experiences, relatively little is known of the impact and subsequent effects of receiving a diagnosis of dementia. In considering the potential consequences, the literature pertaining to chronic illness had been used. Charmaz (1983) reported that one outcome of chronic illness is the disruption to the person's self-concept and the loss of self is considered a

fundamental form of suffering. The disruption to self-concept occurs as a result of a restricted life style, social isolation, discrediting of self and being a burden. Furthermore, concern is heightened regarding the person's perception of the person they are becoming and there is a loss of valued self-images from the past. Consequently, they perceive themselves and their lives as fragile.

#### **1.4. Social psychological models of self and identity**

As mentioned above, self-concept was identified in the literature as a significant factor within chronic illness. Therefore the social-psychological models of self and identity will be reviewed. The first of these is the theory proposed by Tajfel (1982) who stipulated that social behaviour is determined by the person's social identity. If they are identified with a group that has a favourable social identity, then the individual can remain secure and socially valued. However, if the group is not favoured then they may feel less secure and may be motivated to change or move into a more socially valued group. It is proposed that people with dementia are viewed as belonging to a unfavoured social group. However, moving to a socially valued group would not be possible as the diagnosis of dementia remains with them.

Two further social-psychological models, Social Constructionism and Symbolic Interactionism, have been used to illustrate the development of self-identity. The first, the Social Constructionist position is critical of the biomedical model of health and illness as it suggests that this model ignores the social context of the illness and presents its view of 'reality' as '*the* representation' as opposed to '*a* representation' (Vittoria, 1998, p97).

Social Constructionists propose that reality and knowledge are socially constructed through human action (Berger & Luckman, 1966) and therefore medical ideas are the product of this social process. Such ideas continually metamorphose due to social and cultural practices and concerns and not always through developments in our knowledge. Dementia can be viewed as an example of a socially constructed disease, with the medical profession as the 'architects' of this construction (Harding and Palfrey, 1997). These social constructs acquire an objective quality as it is assumed that they represent concrete reality. With respect to self-identity, socially constructed meanings are projected onto and into the individual and therefore it is proposed that a non-dialectical relationship exists between society and the individual.

In relation to Social Constructionism, Symbolic Interactionism proposes that individuals are self-reflective and through social interactions form meanings about their environment (Blumer, 1969). With respect to self-identity, the origin of self is social and thus behaviour is 'constructed'. The self is therefore considered to be active rather than passive. The actions and conversations of one person influence the subsequent actions and conversations made by others and vice versa. Therefore, there is a continuous process of interpretation and re-interpretation, with individuals constructing their realities through the process of interaction. The self changes according to the context. Unlike Social Constructionism, a dialectical relationship is considered to exist between the individual and society. With respect to the development of the self, Symbolic Interactionism focuses on how self-identities are built from the meanings that individuals bring to categories of experience such as sexuality and gender (Harding & Palfrey, 1997). Furthermore, it is

concerned with how self-identity is developed by the individual through the messages given by others. Information may be assimilated through the processes of social comparison and "reflexive appraisal" (Tedeschi, 1984, p5). Individuals scrutinise their social interactions for signs of "discreditation and negative reflections of self" (Charmaz, 1983, p190). With respect to dementia Harding and Palfrey (1997) proposed what seems to be an extreme view that "society produces dementia through the messages sent to older citizens, which they assimilate into their self-identities" (p17). Assumptions and models of ageing lie behind everyday speech and the use of this language may inhibit or restrict older people or even promote their decline (Coupeland, Coupeland, & Giles, 1991)

The concept of stigma discussed earlier can be understood within the models of Social Constructionism and Symbolic Interactionism. According to Goffman (1963)

"Stigma,.. is a societal reaction which singles out certain attributes, evaluates them as undesirable and devalues the persons who possess them.....The individual concerned tends to be defined in terms of his or her stigmatised attribute....The stigma tends to become all-important and to override characteristics; Consequently, possessing an attribute which is stigmatising means that the whole person becomes stigmatised" (p2).

Unlike Goffman who referred to a social process, Scrambler & Hopkins (1990) defined stigma in terms of the subjective experience. These proposed that stigma was the shame felt by the individual in response to having an illness and the fear of discrimination and rejection as a result of this illness. Both definitions are useful in understanding the impact of stigma on the individual and both can be applied to people with dementia. In relation

to Alzheimer's disease, the status of the individual and their identity is considered to change as a result of intellectual decline, of which inferiority and social unacceptability are the consequence (Cottrell and Schulz, 1993).

Breakwell (1986) in her book 'Threatened Identities' proposed a model of identity, threat and coping, comprising a number of components. Her model, although not directly related to dementia, is concerned with factors that may threaten the person's identity. According to this view, the structure of identity consists of two dimensions, namely content and value. The content dimension contains "the properties which taken as a constellation, mark the individual as unique" (p190). The characteristics previously related to social identity (e.g., group membership, roles etc) and personal identity (values, attitudes etc) are contained within this domain, although within this model both are subsumed under the label of 'personal identity'. Positive or negative value is attributed to each element within the content dimension and combined these constitute the 'value dimension of identity'. This dimension is continually subject to revision, and reappraisal of the value ascribed to each element may occur as a result of "changes in social value systems and modifications in the individuals position in relation to such social value systems" (p191). Accommodation-assimilation and evaluation serve to regulate the structure of identity. Breakwell proposes that the identity becomes threatened when these processes are "unable to comply with the principles of continuity, distinctiveness and self esteem" (p192) and threats may originate internally or externally. Having detailed the social-psychological theories of identity it will be important to consider research literature concerning dementia and self-identity.

### **1.5 Self-concept and older adulthood.**

Before considering the potential impact of dementia on self-concept, it is important to first consider whether self-perceptions are influenced by the transition into older adulthood. Empirical research has suggested that self-concept remains considerably stable with age (Baltes & Baltes, 1990). In particular, they suggested that the resilience of self-esteem through physical and social changes refute common expectations. These findings have prompted greater interest in identifying the factors associated with diminished self esteem as it appears that it is not an inevitable feature of aging (Woods, 1996). Wainright (1997) proposed that the loss of social roles, which provide status and the opportunity to contribute to the social network, is the most devastating thing to happen to an older person. Few studies have attempted to investigate the relationship between dementia and self-concept and it is therefore important to consider why these experiences have historically been absent from the research literature.

### **1.6 Why have the subjective experiences of dementia been less prominent in the research literature?**

According to Kitwood (1997) there has been an almost total disregard for the subjective experience of dementia in the research literature. The results of the literature search support this view, however subjective experiences in dementia recently appear to have grasped the interest of several researchers. Various hypotheses have been proposed for its previous absence from the literature. Those that will be reviewed here are, 1) the inferences made about people with dementia with regard to their cognitive abilities 2) the perceived absence of subjective experience, 3) others' self-protective distancing from

people with dementia and 4) the methodological barriers to investigating these phenomenon.

As mentioned, the first category is concerned with the inferences made about the cognitive abilities of people with dementia. Authors have noted that self-reflection and expression by people with dementia is rarely possible (Goldsmith, 1996) and assume that insight is lost by the time the person reaches the moderate stages (Allan & Killick, 1998). The literature pertaining to the various cognitive attributes will be discussed in turn.

Foley (1992) defined insight as:

"The capacity to discern the true nature of the situation, or as applied to dementia, the recognition of the fact, degree and implications of ones own illness" (p37).

He considered it "remarkable" that only "passing reference" was made within the literature to insight in dementia, despite its presence in the literature regarding neurosis and psychosis, and particularly, as so much of patient care and management depends on the person's capacity to understand what is wrong.

Foley (1992) also considered the view that people are unaware of dementia to be an "unfortunate misconception" (p30). However, the research literature suggests that a mixed picture exists. It seems that some people preserve and acknowledge their awareness throughout the course of the disease, while others, although aware that something is wrong, will not admit so, but will resort to methods of denial or concealment (Foley, 1992), such as confabulation, perseveration (Henig, 1988) and



displacement (Reisberg, Gordon, McCarthy, Ferris & De Leon., 1985). With respect to coping styles, Keady & Nolan (1995) discovered that in addition to those described above, some people developed repetitive patterns of behaviour; some collapsed into dependency; while others discovered constructive means of coping, for example, planning carefully or accepting the help offered by others (Kitwood, 1996, p14). In contrast, some people have no awareness that anything is wrong and behave consistently with this belief.

Furthermore, people with dementia may display "windows of clarity" which open and close and which allow for "normal personality and normal intelligence to emerge" and thus there are variations in content and intensity at different times (Foley, 1992, p31). The diversity of presentations described suggests that further systematic study is required. Such research should attempt to consider and answer questions such as those proposed by Foley (1992) below, which have implications for clinical practice:

"What awareness do demented patients have of their deficiencies? What emotional responses do they have to the deficiencies? What is the relationship between insight and emotional response?" (p30)

Goldsmith (1996) argued that communication with people with dementia is possible and although time-consuming and frustrating, it is a process well worth persevering. Having recognised the importance of this view, Winner (1993) has now turned his attention to exploring the means of understanding and obtaining the views of people with dementia. Sperlinger and McAuslane (1994) in a pilot study demonstrated the potential value of seeking the views of people with dementia about the services they received.

Kitwood (1997) further questioned the absence of the subjective experience of dementia.

1. "Is it that people with dementia were considered to have no experiences?
2. Is it that they were no longer deemed to be persons and thus not worthy of consideration?" (p13)

Kitwood (1997) concluded that "whatever argument is given for this flight from intersubjective engagement, it bears the marks of a rationalisation of fear" (p14). (Kitwood, 1997, p14). Kitwood & Bredin (1992) remarked upon the vulnerability of formal and informal carers who are "bearing their own anxiety and dread concerning frailty, dependency, madness, ageing, dying and death" (p270). Objectifying this interpersonal context serves to maintain the carer's psychological defences, making involvement with people with dementia tolerable. Such objectification can serve to "depersonalise or dehumanise" the person with dementia (Kitwood, 1997, p13/14) and distancing oneself from people with dementia serves to exacerbate their experience of loss (Goldsmith, 1996).

Finally, Keady & Gilliard (1997) described the logistical barriers to conducting research with people with dementia. This included "identifying and accessing a theoretical sample, obtaining the subjects informed consent to interview and gaining ethical approval to implement the research" (p3). A further potential barrier is whether people have been informed of their diagnosis of dementia, which will be discussed below.

### **1.7. Giving and receiving a diagnosis of Dementia.**

A debate currently exists regarding the disclosure of the diagnosis to people with dementia. Carers are almost invariably informed of the diagnosis, which subsequently shifts the burden of responsibility (Keady & Gilliard, 1997), but it is unclear what information the patient is given (Heal & Husband, 1998). The literature suggests that open and frank discussion is avoided (McWilliams, 1998). The current status of this debate could be said to mirror that of the oncology literature approximately thirty years previous. Heal & Husband (1998) note that "withholding information about diagnosis clearly contravenes the well-established principle of the patient's right to know" (p144) and was considered unfair and unethical (Black, 1995).

Beliefs which support the withholding of a diagnosis include protection from social stigma (Cundill, 1994), that disclosure would have catastrophic implications (Illiffe, 1994), that people with dementia have no insight or cognitive ability to understand the meaning of their diagnosis (Mullen, Howard, David & Levy, 1996), and that memory impairments cause them to forget and therefore there is no point causing unnecessary distress (Bender & Cheston, 1995). As Heal & Husband (1998) noted, it is a major life event to receive a diagnosis of dementia and one, which may precipitate or exacerbate depression in vulnerable individuals. This view to date has not been supported through research.

Furthermore, confirming an early diagnosis of Alzheimer's Disease is extremely complex and involves systematically excluding other symptomology (Keady and Gilliard, 1997).

Consequently, there is the potential for misdiagnosis, as in pseudo-dementia (Homer et al, 1987). Problems obtaining accurate diagnosis result from uncertainty about the effects of dementia on behaviour (despite the fact that diagnosis is predominantly based on behavioural changes, as opposed to pathology) and consequently the difficulty of developing diagnostic tools which accurately measure the severity of pathological states (Harding & Palfrey, 1997). For example, brief screening tools have been reported to be unable to reliably detect the early signs of dementia (Keady & Gilliard, 1997). Assessment such as the Mini Mental State Examination (Folstein, Folstein & McHugh, 1975) provides only a rough estimate of performance at a single point in time. Furthermore, both this and the CAMDEX (Roth, Huppert, Tym & Mountjoy, 1988) have been criticised for their inability to take account of previous educational levels and skills (Kitwood, 1997a).

The decision made by psychiatrists to give a diagnosis of dementia to patients was found to be dependent upon the level of severity, age of the patient and human conscience (McWilliams, 1998). However, even when the diagnosis is shared, the prognosis is rarely communicated (Rice & Warner, 1994). The views and wishes of carers further complicate disclosure. In one study, a large proportion of carers (83 percent) did not think that their relatives should be informed of the diagnosis (Conor, Kirby, Coen, Coakley, Lawlor & O'Neill 1995). The most common reason for withholding a diagnosis was the distressing nature of dementia (Maguire, Kirby, Coen, Coakley, Lawlor & O'Neill, 1996), the stigma associated with the diagnosis and that this may extend beyond the patient to family members and acquaintances (Heal & Husband, 1998). An

overwhelming reason for disclosure by carers was that the person had asked to know and they required some meaningful explanation for their problem (Heal & Husband, 1998).

Rice and Warner (1994) concluded that "patients have the right to know their condition" and that "people with mild dementia should be given enough information for them to understand the diagnosis and prognosis" (p470). Although currently unproven for dementias, the benefits of giving a diagnosis from other domains of medical practice, suggest that disclosure allows consultation with the sufferer about the future e.g., financial arrangements, living wills (Heal and Husband, 1998). One study found that when told, sufferers said they would rather know than face the uncertainty of ignorance about their experiences (McWilliams, 1998). A daughter who after much deliberation shared the diagnosis with her mother recounted that "this openness meant that the full meaning of Alzheimer's Disease could then be shared and jointly used to understand and manage the experience of forgetfulness" (Black 1995, p10). Furthermore, the development of new drug treatments for dementia requires the disclosure of a diagnosis for informed decisions by participants.

### **1.8. Research into the subjective experience**

Although historically the subjective experiences had not been investigated, Kitwood (1997) reported that considerable progress had been made in this area in a very short period of time, after being placed on the agenda by Froggatt (1988). However, subsequent investigations primarily involved people with only mild cognitive impairments (Keady, 1996). Kitwood (1997a) proposed six access routes to exploring the

subjective experience of people with dementia. The first three described are obtained through the personal accounts written by people with dementia, through discourse within the context of a group or interview and by attending to actions and discourse in every day life. The final three concern consulting people who have experienced an illness which has 'dementia-like features', through our "poetic imagination" and finally through role playing a person with dementia in a simulated environment (p73). Only the first two will be discussed here as they involve systematic study. Techniques such as role-play are considered more likely to represent "the hidden memories of role players" and are therefore not considered representative of the actual subjective experiences.

Personal accounts of people with dementia have provided invaluable insights into the subjective world of dementia. Davis (1989) author of 'My Journey into Alzheimer's Disease' and McGowen (1993) author of 'Living in the Labyrinth' have both provided such insights through their works. Both expressed their distress about the period of time taken to establish a diagnosis, results of assessments being withheld, the absence of support services and memory training and the inadequate supply of information (Keady & Gilliard, 1997). Furthermore, McGowen described a variety of feelings including "paralysing fears". The strongest of these is the fear of abandonment or the death of her spouse. Further experiences include a lack of self worth, feelings of guilt concerning dependency and inability, frustration as a result of failing abilities and the ignorance of others. Heightened sexual desire and changes in behaviour such as the development of obsessive traits as a means of imposing a sense of security were also cited. McGowen's

accounts of her subjective experiences are extremely striking as the following extract demonstrates.

"If I am no longer a woman, why do I still feel one? If no longer worth holding, why do I crave it? If no longer sensual, why do I enjoy the soft texture of silk against my skin? If no longer sensitive, why do moving lyric songs strike a responsive chord in me? My every molecule seems to scream out that I do, indeed, exist, and that existence must be valued by everyone! Without someone to walk this labyrinth by my side, without the touch of a fellow traveller who understands my need of self-worth, how can I endure the rest of this uncharted journey?" (McGowen, 1993, pp. 123-124).

One can clearly gain considerable insights into the subjective world of dementia through such writings. These authors however are clearly very articulate and therefore this would not be a route accessible to all. Thus, the second access route proposed was interviews or groups. Several researchers found evidence for the capability of those people even within the severe stages to meaningfully express themselves through words (e.g., Barnett, 1996; Goldsmith, 1996). To achieve this authors suggest that one needs to undertake careful listening, paying close attention to "metaphor, oblique allusion" and "verbal and non-verbal registers" (Kitwood, 1997, p15). The subjective experiences identified by such studies included the fear of being out of control and being perceived as such, feeling lost and meaning disappearing, concern about being a burden and the desire to be useful. Furthermore, they described anger and resentment towards the dementia and its impact on their lives. In contrast, an acceptance of their disabilities and gratitude about having

previously experienced good things were reported. Balfour (1995) through the administration of the TAT (Thematic Apperception Test) elicited the sense of deepening despair, giving up and the desire for closeness and comfort.

Cheston (1996) suggested that during group work, descriptions of past events and experiences are often rich in metaphors regarding their current circumstances. Telling life stories, through individual or group work such as reminiscence therapy (Mills & Coleman, 1994) helps to preserve continuity and a coherent sense of self. However, the past itself can be a source of disturbance (Coleman, 1986) and therefore Haight, Coleman & Lord, (1995) have provided useful guidelines for conducting life review counselling.

Kitwood's (1997) third access route is to "attend carefully and imaginatively to what people say and do in the course of their ordinary life" (p16). He suggested that as in therapeutic work, the observer needs to think beyond the literal meaning of behaviours and needs to make interpretations about these. Little systematic research has been conducted in this area to support this suggestion.

In addition, Kitwood (1997) noted that behaviour patterns most often undergo changes during dementia and as a result considered how difficult life may be for the person. He noted that together with the progressive failure to understand such changes, people are also confronted with other people's reactions, which may be unhelpful or unfamiliar. Kitwood thought it advantageous to consider a continuity of personality instead of a radical change. Resources may be lost as a result of neurological impairments, but these



may be further compounded or exacerbated by social-psychological factors such as other peoples' reactions mentioned above.

Behaviour change and potential subjective experiences could be considered in relation to process models such as Kubler-Ross's (1969) stages of adjustment to terminal illness, which dementia ultimately is. The sequence of adjustment occurs in six stages, denial, bargaining, anger, despair, resignation and acceptance. Keady & Nolan (1994; 1995-b) developed a nine-stage model through their interviews with people with dementia. The first stage is "Slipping", whereby the person recognises minor and trivial memory lapses. Emotional-focused coping strategies, such as "normalising" or "discounting" events are used during this stage as a means of denial. The second stage is "Suspecting", where such memory lapses increase in frequency and severity and can no longer be "rationalised or ignored". The suspicion of something being seriously wrong emerges. "Covering up" is the third stage whereby the person makes both a "conscious and deliberate effort" to conceal and compensate for their difficulties. However, with the progression of dementia, concealment falters and the person begins to recognise changes in the level of behavioural activities and cognition. The person thus moves into the fourth stage of 'Revealing' whereby difficulties become revealed to closest others. Shared knowledge remains within the family and confirmation of their suspicions is delayed. Acknowledgement of the problem and the process of obtaining a formal diagnosis occur in stage 5 of "Confirming". Adjustment to dementia and the use of adaptive coping strategies to compensate for losses occurs during the stage of "Maxising". As the dementia progresses, the behavioural and cognitive problems become the dominant

feature through which "Disorganisation" occurs. A loss of subjective awareness regarding their actions ensues alongside diminishing decision-making abilities. The eighth stage of decline encompasses increased dependency and the 'instrumental demands of care', and decision-making regarding the need for residential care often occurs here. The final stage in this process is death.

### **1.9 Clinical Implications**

As described above Breakwell (1986) proposed the existence of a relationship between identity and coping. For those people with a dementing disease one of the most common features is depression (Reifer & Larson, 1989) and the prevalence rate of depression in many dementing disorders was between fifteen and fifty seven percent (Heal & Husband, (1998). It is predicted that for patients with primary organic dementia, one quarter to two-fifths will experience clinically significant depression during the course of their illness (e.g., Lazarus et al., 1987).

Depression may develop in response to the subjective appraisal of receiving a diagnosis of dementia and of the recognition of either current or forthcoming cognitive and functional decline. Depression can impede coping strategies, superimpose the decline in functioning (Foley, 1992) and exacerbate cognitive problems particularly memory (Lezak, 1995). Understanding the subjective experiences of dementia in relation to the impact upon self-concept can provide insight into the potential psychological consequences, which will be valuable for clinical intervention. For example, recognising the functional cause of cognitive and behavioural decline potentially renders the

symptoms reversible. These findings would also be important when considering the provision of care in residential settings (Kitwood & Bredin, 1992).

### **1.10 Summary of the literature**

The review of the literature suggests that many authors are of the opinion that a predominantly biomedical understanding of dementia had developed, which they feel had a detrimental impact on how people with dementia are viewed. It was however recognised that dementia needs to be viewed from a holistic perspective. Therefore it was noted that the significant contributions made by the medical profession to our understanding of dementia should not be dismissed.

The social psychological models of identity were reviewed. These included Tajfel's (1982) theory of social identity, social constructionism and symbolic interactionism. Primarily, these theories suggest that identity develops and is evaluated through social interactions. The exclusion of the subjective experiences of dementia from the research literature were discussed and a review undertaken of the research studies available.

### **1.11. Using qualitative methodology**

The choice of methodology is dependent upon the nature of the problem to be investigated. Three 'valid' reasons for using qualitative research have been proposed (Strauss & Corbin, 1990). First, research projects, which aim to discover subjective experiences such as illness, are considered to 'naturally lend themselves to qualitative types of research. Second, qualitative methodology can be used to discover phenomena in

an area in which little is known or has been done. Chenitz and Swanson (1986) suggested that this is where grounded theory "makes its greatest contribution" (p7). Finally, qualitative methodologies can illicit intricate details, which would be difficult to obtain using quantitative methods. Strauss and Corbin (1990) describe a grounded theory as "one that is inductively derived from the study of a phenomena it represents. The researcher begins with an area of study and relevant information emerges from the data. They do not begin with a theory to prove or disprove. The aim of this approach is to build theory 'that is faithful to and illuminates the area under study' (p24)

The current research aimed to explore the subjective experiences of people with dementia. A qualitative design was employed which is supported by the rationale described above. The researcher is investigating subjective experiences about which very little is known. The aim is also to obtain intricate details about the subject investigated.

Smith (1995) commented upon reflexive practices, which emphasise the researcher's awareness of their own presence in the research project. Strauss & Corbin (1990) referred to "Theoretical Sensitivity" whose sources are literature, and professional and personal experiences, which the researcher brings to the research situation (p41). The analytic process itself was also identified as a source of theoretical sensitivity. They refer to Theoretical Sensitivity as the "ability to recognise what is important and to give it meaning" and to maintain a balance between what is real and what is created by the researcher.

The researcher recognises that the research questions were guided by Breakwell's (1986) model of threatened identities. The five research questions were based upon the two dimensions, namely content and value and are as follows:

### **1.12 Research Questions**

1. What problems do people with dementia recognise?
2. How does this awareness affect how people with dementia feel about themselves?
3. What is the effect of dementia on relationships as perceived by the individual with dementia?
4. What is the effect of dementia on their involvement in activities and interests as perceived by the individual?
5. How do perceived changes affect how people with dementia feel about themselves?

## **2. Method**

### **2.1. Design**

A cross sectional qualitative research design was employed following the method of Smith (1995) and also drawing on grounded theory methodology (Strauss & Corbin, 1990). The principles of content analysis (Krippendorff, 1980) were employed to measure participants' recognition of their symptoms of dementia. A semi-structured interview was developed to address the research questions and data were obtained through face to face interviews. Participants were seen on two occasions. The first interview was concerned with administering two questionnaires to establish inclusion criteria, and also to address any queries. During the second, the semi-structured interview was administered.

### **2.2. Participants**

Ten participants, five male and five female were recruited from four services (termed by the numbers 1-4 here), two from service one, two from service two, three from service three and three from service four. The age range of participants was 63-90 years with a mean age of 76.5. Detailed participant characteristics are given in Table 2 in the results section.

#### **2.2.1. Theoretical Sampling**

Qualitative research methods adopt a theoretical as opposed to a representative approach to sampling as employed for quantitative methods (Glaser & Strauss, 1967). Participants were selected on the basis that they could provide information regarding the phenomena investigated.

### 2.2.2. Recruitment of Participants

The inclusion criteria stipulated that participants:

- i) were 'older adults' (over the age of sixty)

It was hypothesised that the experiences of people with early onset dementia may differ from the older adult cohort, since this was not to be addressed in this research, those with early onset dementia were excluded.

- ii) had been diagnosed with a dementia in the mild to moderate range of severity, thus scoring between twenty-four and sixteen on the Mini Mental State Examination. Participants scoring above twenty-four (indicating a high level of functioning) who had undergone additional assessments e.g., neuropsychological assessments, which suggested the presence of dementia were also included (see section 2.5. for a more detailed discussion.)
- iii) had been informed of a diagnosis e.g., Memory Problems.
- iv) could participate in a semi-structured interview.
- v) were able to provide informed consent to participate in the research.
- vi) spoke English as a first language.

See section 2.3. 'Ethical Considerations' for further details of the inclusion criteria.

Participants were excluded if:

- 1) they had additional severe mental health or physical problems which might also impact on self-concept.

Many potential participants identified could not be included. Below are details of those identified within each service and Table 1 illustrates the reasons for exclusion.

### Service one (Trust 1)

The service consisted of three Community Mental Health Teams for Older People serving three geographical locations. Potential participants were identified from the caseloads of the Mental Health Team workers. Seventy-two people were identified. Potential participants were also identified through their attendance at the Day Hospital, which provided services to clients receiving services from the three teams.

### Service two (Trust 2)

This service consisted of five Community Mental Health Teams for Older People serving five geographical locations. Potential participants were identified from a 'Dementia Care Register', a computer database containing information about each person diagnosed with dementia within the Trust. Each person had provided consent to be approached for research purposes and could be involved in only one research project at a time. Forty-seven people were identified as potential participants for this project.

### Service three (Trust 2)

This service consisted of three Community Mental Health Teams for Older People serving three geographical locations. Potential participants were identified from the caseload of a Clinical Psychologist. Sixteen people were identified.



## Service 4 (Trust 3)

This service consisted of a Community Mental Health Team for Older Adults. Potential participants were identified through their attendance at the day clinic. Three people were identified and all took part.

**Table 1: Reasons for the exclusion of potential participants from the research for each service**

Reason For Exclusion	Number Excluded		
	Service 1	Service 2	Service 3
<b>Phase 1: Information obtained from participants medical records</b>			
Severity of Dementia	26	2	
Long term mental health problems	4		
First language not English	8		
Known to researcher	1		
Not receiving mental health services e.g., moved	1	21	1
Early onset Dementia		4	1
Concerns about mental status or mental health			2
<b>Phase 2: Information obtained from the completed 'keyworker Questionnaire'</b>			
Not received a diagnosis of dementia or query dementia (e.g., depression, alcohol induced)	6		1
Not told actual or alternative diagnosis	2		1
Deterioration in mental status or mental health	1	1	
Did not meet inclusion criteria	3		
Withdrawn (No reason given)	2		
'Keyworker Questionnaires' not returned	4	1	
Keyworker's Concern about participants involvement e.g., bereavement/anxiety re: research		2	
Unable to participate in interview		1	2
Significant physical illness			1
Does not wish to participate			1
<b>Phase 3: Information obtained from Consultant Psychiatrist</b>			
Not diagnosed with dementia	1		
Not told their diagnosis	1		
Withdrawn (No reason given)	5		
<b>Phase 4: Information obtained from carers or family members</b>			
Did not wish participant to be involved	1		1
Deterioration in mental status or mental health	1	1	1
Too many professionals involved	1		1
No response	2		
<b>Phase 5: Information obtained from potential participants</b>			
Did not wish to participate in research	2	3	
Did not respond		9	
<b>Total</b>	<b>72</b>	<b>45</b>	<b>13</b>

### **2.3. Ethical Issues**

The BPS Code of Conduct (1993) and the DCP Professional Practice Guidelines (1995) were consulted and adhered to regarding the numerous ethical considerations associated with this research. Three NHS Trusts granted ethical approval (Appendices 1-3). The following procedures were undertaken to ensure that the necessary ethical considerations were addressed.

#### **2.3.1. Use of Terminology**

The researcher's initial aim was to recruit participants informed of their diagnosis of dementia to avoid disguising the nature of the study. However, it emerged during the initial recruitment process that differing clinical practices were in operation as to whether a diagnosis of dementia was disclosed to service users and their carers (See section 1.7. for a full discussion of the current debate). The actual information provided to service users and their carers was not routinely documented in medical files and mental health workers were often unable to provide clarity.

It seemed that despite dementia being diagnosed, service users were often told that they had 'memory problems'. Given the difficulties encountered in obtaining clarity about the information provided to service users, the researcher was advised by both research and field supervisors to use the blanket term of 'memory problems' to prevent any unplanned disclosure of the full diagnosis. Permission was sought and granted from the Local Research Ethics Committees to replace the term 'dementia' with 'memory problems'.

### 2.3.2. Information Sheet

The 'Information Sheet' (Appendix 4) outlined the nature, purpose and procedures of the research. The limits of confidentiality and anonymity were stipulated along with the participant's right to withdraw from the research. All of the information contained within the information sheet was reiterated and questions answered at the beginning of each face-to-face interview to allow for potential difficulties retaining information.

### 2.3.3. Informed Consent

Mental health professionals working alongside participants were consulted to insure that participants could consent to participate in the research. Consent forms were completed on three separate occasions, to account further for the potential difficulties retaining information between interviews. 'Consent Form One' (Appendix 5) was distributed to potential participants together with an introductory letter and information sheet. If in agreement, potential participants consented to be contacted by the researcher. During the first meeting participants consented to the administration of the Mini Mental State Examination (Folstein, et al, 1975) and the Geriatric Depression Scale 15 (Sheikh & Yeasavage, 1986) (Appendix 6) and during the second meeting, to participate in the semi-structured interview (Appendix 7).

### 2.3.4. Monitoring potential distress

Participants were recruited through their involvement with mental health services to insure that support would be available should they experience distress. Ethical Approval was obtained to continue to recruit people from the 'Dementia Case Register' (Service 2)

after it emerged that many were no longer receiving mental health services. In this instance, it was agreed that if required the researcher would provide participants with the details of appropriate services e.g., voluntary agencies. The emotional status of participants was monitored throughout the interview and participants were debriefed on completion and provided with a contact number for the researcher so that any issues emerging following their involvement in the interview could be discussed.

#### 2.3.5. Professional Considerations

Permission to conduct the research within each service was obtained from the Consultant Psychiatrists providing medical responsibility and the Clinical Psychologists providing psychological responsibility for the participants. In service one it was mandatory for the research to be registered with the Research and Development Committee.

### 2.4. Procedure

#### Phase 1:

Mental health workers identified potential participants. The medical files were consulted to establish whether the inclusion criteria were met. Those people who did not meet the criteria were excluded from the research.

#### Phase 2:

The generic term 'Keyworker' will be used to refer to those mental health workers (e.g., Community Psychiatric Nurses, Occupational Therapists, Psychologists etc) who provided mental health services to individual participants.

Keyworkers completed a 'Keyworker Questionnaires' (Appendix 8) to confirm that potential participants met the inclusion criteria and they were also asked if:

- i) they would provide potential participants with information about the research
- ii) participants had been seen within three months to exclude the potential for further cognitive decline or deterioration in mental health
- iii) a carer or family member should be contacted in the first instance.

### Phase 3:

Permission was obtained from the Consultant Psychiatrists to contact specifically those individuals who met the inclusion criteria and their carers.

### Phase 4:

For all but service two, one of two procedures was employed. In the first scenario, participants were approached directly by keyworkers. Keyworkers were provided with guidelines for this procedure (Appendix 9). Participants were provided with an introductory letter (Appendix 10) and information sheet (Appendix 4), which was read to them if necessary. In scenario two, a carer or family member was contacted in the first instance. Ethical approval was granted to undertake the procedure considered most appropriate for each participant, based upon the clinical advice of keyworkers. Carer involvement was considered appropriate when cognitive problems could prevent willing participants from engaging in the research or when they could assist the participant in making an informed choice about participation. In some instances the involvement of carers would not be beneficial as it could be experienced as undermining to capable and

independent participants, thus inappropriately reinforcing perceptions of disability and dependency.

During the initial recruitment process, it emerged that a majority of people named on the 'Dementia Case Register' were no longer in contact with the Mental Health Services. As this was initially a pre-requisite of the research, further ethical approval was obtained to contact people directly through written correspondence. Participants identified from service two were sent an introductory letter (Appendix 11) and an information sheet (Appendix 4). These were also copied to a carer or family member for the same reasons as those described above.

#### Phase 5:

Participants were visited at home on two occasions. This allowed for familiarity to develop between the researcher and the participants, the benefits of which have been described by Sperlinger and McAuslane (1994), and it drew a distinction between the formal assessment procedures (see section 2.5. 'Measures') and the semi-structured interview. Completing both procedures during a single session was also considered too demanding for many people with dementia.

## **2.5. Measures**

### **2.5.1. Severity of dementia**

The Mini Mental State Examination (Folstein et al, 1975) (Appendix 13) was administered to assess dementia severity. The MMSE is a well established clinical and research instrument. It was devised and is routinely used as a screening tool and was used for this purpose here. It was chosen for its brevity and ease of administration. No other assessment tools were considered suitable for the purpose of screening for this research. Scores of twenty-four and below indicated the presence of dementia (Lezak, 1995, p741). Participants scoring between sixteen and twenty-four were considered to fall within the mild-to-moderate stages of dementia and were thus included in the research. The MMSE is limited in that it can only provide an estimation of the participant's mental status at a point in time (Kitwood, 1997). Therefore, participants scoring above twenty-four, who had undergone additional assessment suggesting the presence of dementia were also included. The MMSE is not influenced by the presence of depression (Lezak, 1995).

### **2.5.2. Depression**

The Geriatric Depression Scale-15 (Sheikh & Yeasavage, 1986) (Appendix 14) was administered to assess the presence and severity of depression. Depression is a common clinical feature amongst people with dementia and can impact upon self-perception (See section 1.9). Participants were not excluded on the basis of the presence of depression. The scale was used to inform the researcher about the emotional status of the participants for two primary reasons. First, to assist in the monitoring and avoidance of potential distress. Second, to consider the potential impact of the presence of depression on the

interview process and participant responses. Like the MMSE, the GDS-15 is a well established clinical and research instrument. The four scoring categories are as follows; 0-4 non-depressed, 5-9 mild, 10-12 moderate & 13-15 severe (Boddington, Krasucki & Cook, 2000).

## **2.6. Developing the Interview Schedule**

A Semi-structured Interview was developed (Appendix 15) to address the research questions. The development of the research was guided by a comprehensive literature review. Within both the grounded theory and IPA (Smith, 1995) methodology, interview questions begin more broadly with limited prompting and become progressively narrow as relevant concepts and their relationships emerge (Strauss & Corbin, 1990). When designing the interview schedule it was essential to consider the potential impact of cognitive limitations on the interview process. For example, simple language structures were used involving only one idea or concept. It was envisaged that the vagueness of broad questions could be difficult for some participants to grasp. Even so, it was considered important to try to avoid premature closure by beginning in a too structured way. Therefore, in line with the grounded theory approach, open questions were used to promote the spontaneous emergence of themes. A series of prompts were then introduced when open questions were difficult to answer and also to encourage further recall.

The interview was scrutinised by Clinical Psychologists who had experience of interviewing people with dementia through clinical practice. Two pilot interviews were also undertaken with people with dementia. The first pilot interview demonstrated that



specific memory and associated problems were not initially being acknowledged through open questioning. This identified the need for a series of prompts as discussed above. The amended interview schedule was piloted and no further changes were required.

### Interview Schedule (see Appendix 15)

#### **Pre-interview briefing:**

The aims and purpose of the research were explained to the participant, along with the maintenance of confidentiality and anonymity and the participants' rights to withdraw. Written consent was obtained from all participants.

#### **Section 1: Orientation**

The initial aim was to insure that participants were orientated to the topic. The pre-interview briefing assisted this process. Questions focussed on the onset of the memory problems, who initially recognised these, and the terminology used by the assessing mental health professionals.

#### **Section 2: Recognition of the symptoms of dementia**

Open questions were used to elicit the participants' spontaneous recognition of their memory and associated problems. A series of nine prompts were used when spontaneous recognition was exhausted or when participants had difficulty recalling examples. These prompts were common features of dementia as stipulated in the research literature (APA, 1994).

### **Section 3: Exploring the experience of the symptoms of dementia**

Participants were asked to describe their experiences of each symptom of dementia recognised. This was achieved by eliciting recent examples and assisting the participant in retracing the order of events.

### **Section 4: Impact of the recognition of the symptoms of dementia on self-concept**

Participants were asked how the experiences described made them feel.

### **Section 5: Perceived changes in relationships and associated roles and activities**

Participants were asked how they would describe their current significant relationships. Shared time, interests and designated roles within these relationships were explored. These were compared to descriptions of the same relationships prior to the onset of dementia. Specific changes identified within these relationships were explored further.

### **Section 6: Impact of perceived changes on self-concept**

Participants were asked to describe how these perceived changes in their relationships made them feel.

### **Section 7: Debriefing**

Participants were asked if the research had raised any issues or problems for them or if they had any questions they wished to ask. The details for contacting the researcher were reiterated. Participants were also asked if they would be interested in receiving a summary report of the results of the research.

## **2.7. Qualitative Data Analysis**

The data was analysed using Interpretative Phenomenological Analysis (Smith 1996). Initially only one transcript is analysed before identifying patterns across cases (Smith, Harre & Van Langenhove, 1995). The individual transcript is read through several times so that the researcher becomes familiar with the content. In the left margin, preliminary thoughts considered relevant to each research question were noted. The right margin was used to note themes that were emerging from the data. Once the first transcript was analysed the themes identified were transferred onto a separate sheet of paper, where connections between them were identified. Related themes were clustered together and given a category heading (Smith, 1995). As new clusterings emerged these were checked against the transcripts to ensure that such clustering made sense for the 'primary source material'. This procedure was repeated for the remaining transcripts and categories from each were amalgamated. Verbatim extracts have been used within the results section to exemplify each category.

### **2.7.1 Validity and Reliability**

#### ***A. Auditability:***

This validity check requires that sufficient evidence is presented to allow the reader to undertake an interpretative dialogue with the data. The processes undertaken in this research were made explicit so that others could follow the steps undertaken by the researcher (Stiles, 1993). An account of the steps taken has been provided in the previous section titled 'Qualitative Data Analysis'. The themes presented were illustrated with verbatim quotes extracted from participants' transcripts (Smith, 1996). It is also possible

to review in Appendix 16 a full transcript with codes. These codes are later listed in Appendices 17-19 within the themes and categories. The researcher also completed a reflective diary throughout the duration of the research (Appendix 20). The accounts documented should allow the reader to see the researcher's frame of reference and its significance in developing the themes and categories (see page 5 of the research diary in conjunction with Appendices 16-19).

*B. Independent Audit:*

The data should be organised so that an independent auditor, could follow the coherent chain of arguments from the raw data through to the final report. The auditor assesses the written account for the credibility of the data collected (Smith, 1996). One way of achieving this is by reading the transcripts and undertaking part in the analysis, using the procedure for data analysis described by Smith (1996) which was summarised in section 2.7. Once the auditor had identified themes and categories these were compared against the analysis undertaken by the researcher. When discrepancies in the data analysis arose, these were discussed and as a consequence, codes were either re-labelled or two codes were combined to form one category. This procedure promotes reflective practice and improves the validity of the research.

*C. Respondent Validity:*

This procedure allows the researcher to determine the extent to which the data analysis reflects the experiences of the participants. The themes and categories elicited from the data were verbally presented to two participants to provide them an opportunity to agree

or disagree with the researcher's account (Prosser & Bronley, 1998). The diagrammatic representations of the findings were also presented to the participants. This provided them with a visual reference, which aided and maintained orientation and concentration and made the verbal material more concrete. A summary of the respondent validation study is provided in section 3.8.

*D. Generativity:*

The standard of the research is evaluated according to its clinical implications and ability to generate further research (Henwood & Pigeon, 1995). This research is clinically informative and suggests a number of potential further research questions. These are detailed in the discussion.

*E. Transferability:*

Transferability is a constructivist approach which refers to the extent to which the research findings can be generalised and transferred to other contexts (Guba & Lincoln, 1990).

### **3. Results**

This section will be concerned with the presentation of the demographic details of participants, an illustration of the participants' recognition of their memory problems and the analysis of the qualitative data.

#### **3.1. Demographic details and inclusion criteria**

**Table 2: Demographic characteristics, Mini mental state examination scores (MMSE) and Depression (GDS-15) scores for all participants.**

Participant Name *	Sex	Age	Marital Status	Residence	Dementia Type	MMSE	GDS-15
Dorothy	F	77	Married	Residential home	Alzheimer's	16	11 (moderate)
Rose	F	72	Married	Marital Home	Alzheimer's	25	08 (moderate)
Anne	F	82	Widowed	Living Alone	Alzheimer's	23	10 (moderate)
George	M	70	Married	Marital Home	Alzheimer's	16	07 (moderate)
David	M	79	Married	Marital Home	Alzheimer's	20	04 (Non-depressed)
June	F	79	Widowed	Living alone	Unspecified	19	9 (moderate)
Charles	M	63	Married	Marital Home	Unspecified	30	2 (non depressed)
Margaret	F	90	Single	Residential home	Lewy-Body	22	13 (severe)
Donald	M	78	Married	Marital Home	Multi-Infarct	23	13 (severe)
Stan	M	86	Married	Marital Home	Frontal-Lobe	23	4 (Non-depressed)

\*All names have been changed to protect anonymity

Most participants met the inclusion criteria of mild to moderate dementia as measured by the MMSE in the first interview. The higher scores signify better functioning. Two participants scored above 24, which is the cut off score for mild dementia, however, their diagnoses had been confirmed by other comprehensive assessments. There was variability in depression scores, ranging from non-depressed through to severe.

**Table 3:** Participants spontaneous and prompted recognition of their symptoms of dementia.

Participant	Spontaneous recognition of memory & other associated problems	Forget things that happened recently	Forget the names of people you know	Difficulty finding the right word	Ask/say the same things more than once	Confused about the time of day	Confused about where you are	Difficulty planning & organising	Worry about meeting new people	Worry about going to new places	Spontaneous recognition of other Problems
Dorothy	Memory Gone. Writing e.g., letters		✓	✓	✓	✓		✓	✓	✓	
Rose	Not making sense. Forget conversations	✓	✓	✓*	✓*	✓		✓	✓		
Anne	Spelling, Losing track of conversation	✓	✓	✓	✓	✓	✓	✓			Deteriorating vision
George	Deterioration in speech – vocabulary Names of long term acquaintances	✓	✓	✓		✓					Problem with legs & balance
David	Nothing Questions regarding orientation e.g., date	✓	✓	✓*			✓	✓			
June	‘Mind goes blank’		✓	✓*	✓	✓	✓			✓	Depression Bereavement
Charles	Effect: ‘Intelligence’ Self-expression. Concentration Gaps in thought	✓		✓		✓ <sup>1</sup>		✓		✓	Deafness. Nocturnal incontinence
Margaret	Confusion: events conversation. Forget- facts, words/names	✓*	✓*	✓*	✓	✓ <sup>1</sup>	✓	✓		✓	Deteriorating sight & hearing
Donald	All aspects of memory Getting lost	✓	✓		✓	✓ <sup>1</sup>	✓*	✓		✓	Paralysis- arm. bladder Problems
Stan	Forgetting items required & significant occasions					✓ <sup>1</sup>	✓ <sup>1</sup>	✓		✓	Fall asleep easily

✓ Symptoms of dementia recognized by participants’

✓ \*Spontaneous recognition

<sup>1</sup>On waking only

### **3.2. Participants' recognition of their symptoms of dementia**

Table 3 illustrates participants' spontaneous and prompted recognition of their memory problems and other symptoms of dementia. All participants spontaneously mentioned their experiences of two or more symptoms and a further four or more symptoms when prompted. The mean number of symptoms spontaneously identified or elicited through prompts was eight. Only David during direct questioning, initially reported experiencing no problems, but later identified a total six, four with and two without prompting.

Of the nine symptoms of dementia specifically investigated the following were mentioned either spontaneously or following prompting. 'Confusion about the time of day' was mentioned most, by all but one participant (N=9). Four participants spontaneously reported that such confusion only occurred on waking either in the morning or during the day. All but two participants (N=8) mentioned their experiences of 'forgetting names', 'difficulty finding the right word' and 'difficulty planning and organising'. These were followed by 'forgetting things that have happened recently (N=7), 'asking or saying the same thing more than once (N=6), 'confusion about where you are' (N=6) and 'worrying about going to new places' (N=6). The symptom least mentioned by participants was 'worrying about meeting new people' (N=2).

### **3.3. Introduction to the analysis of the qualitative data.**

In the initial stages of analysis, approximately 3000 codes were elicited. Codes were grouped into themes and super-ordinate categories through a continual process of analysis. The results have been divided into three key areas, which emerged from the data



and which correspond to the research questions. In summary, the areas are 1) participants' reactions to recognised symptoms of dementia 2) participants' responses to others people's reactions to their symptoms of dementia 3) participants' reactions to the loss of activities as a result of dementia. Insights into the participants' self-perception in relation to each of the three areas also emerged from the data. There was no evidence of sub-groups of participants according to their responses. For example, those people diagnosed with Alzheimer's did not provide particular kinds of responses that differed from those with other diagnoses. In contrast, participant responses were very diverse.

The researcher attempted to adopt a neutral stance and to refrain from imposing a view of the world during the analysis. The themes and categories emerged from the data. However, the labels used were influenced by the researcher's frame of reference (See research diary appendix 20). The categories and themes will be illustrated by exemplary quotations. The number of participants who mentioned each theme is identified in brackets.

### **3.4 Participants' responses to their recognition of their symptoms of dementia.**

Three super-ordinate categories were derived from the data 1) participants' immediate reactions to an episode of e.g., forgetting 2) management strategies and 3) negative self-perceptions. The three conceptual categories and corresponding themes are illustrated in table 4 and are discussed below. See Appendix 17 for the full range of responses provided by participants within each theme.

**Table 4: The number of participants who mentioned each theme concerning their responses to their recognition of their symptoms of dementia.**

Categories	Themes	No. of Participants
Immediate Reactions	Negative Emotional Reactions	8
	Adjusted Emotional Reactions	3
	Cognitive Reactions	5
	Denial	3
	Avoidance: Social Avoidance & withdrawal	3
	Avoidance: Minimising	4
	Acceptance	3
Management Strategies	Social Interventions	7
	Practical Strategies	5
	Cognitive Strategies	6
	Hopeful waiting	5
Negative Self-perceptions	Personal Attributes	3
	Intellectual Abilities	5
	Ageing	1

**3.4.1. Immediate Reactions to a recent episode of the symptoms of dementia.**

Participants described seven types of initial reactions.

**(a) Negative Emotional Reactions**

A majority of participants mentioned a variety of negative emotions (N=8). These ranged from the 'awfulness' and 'strangeness' of experiences to the provocation of sadness, worry, anger and guilt.

June                'Oh, it was horrible, really terrible'

Dorothy           'Horrible. Horrible. ...Just knowing that its going to stay like that'.

**(b) Adjusted Emotional Reactions**

A few participants' reported changes in their reactions to their symptoms of dementia across time, which suggests a process of adjustment (N=3).

George            'It doesn't worry me anymore'

June                'I don't care two hoots now...So I forget, so what?...No, it didn't worry me at all.'

**(c) Immediate Cognitive Reactions**

Half of the participants mentioned cognitive reactions to their symptoms of dementia (N=5). These include confusion, questioning and ruminating. An example of questioning is as follows.

Stan                'I think "Now, where am I? What am I doing?"'

**(d) Denial**

Three participants seemed to be expressing denial at times, by attributing their symptoms of dementia to the ageing process.

Charles            'I put it down to growing old'

**(e) Avoidance: Social Avoidance and withdrawal**

Three participants mentioned their desire to avoid or withdraw from social interactions.

Rose                'Wanting to run away and wishing there was a corner you could disappear into.'

**(f) Avoidance: Minimising the problem**

A few participants minimised the significance of their problems and indicated that they were not concerned by them (N=4)

Charles            'I don't let it worry me and if you don't worry about something it is not so important.....There is no point in getting rattled about it.'

**(g) Acceptance of the symptoms of dementia/Normalising**

Participants' demonstrated their acceptance of their symptoms of dementia in two ways. First, through verbalising their acceptance and second, by normalising their symptoms through social comparison with other people with dementia (N=3).

June            'A lot of people there [day centre], they forget the same as me....You've got to have something wrong with them to be in a place like that [day centre]. You see that's how you know that there is something wrong with each of us.

**3.4.2. Management Strategies**

Four themes emerged from the data.

**(a) Social Interventions**

A majority of the participants mentioned social interventions (N=7). These included, admitting the problem, actively seeking answers, for example, by asking others, receiving prompts from others and being accompanied when travelling to prevent becoming lost.

June            'I say to people "Sorry, I am not good at names". Well it helps because you speak up, you say "Look forgive me, but I forget names"'.

**(b) Practical Strategies**

Half of the participants mentioned the implementation of practical solutions to manage their symptoms of dementia (N=5). Strategies such as written prompts, including calendars and diaries, the use of timepieces and careful planning were described.

Anne            'I have got all my shopping lists there. Look....I kept them from way back, from when I started. And I go back on here more than anything to find out what I want..... I either get the tin or the jar of what I have got left and copy what is on it'

**(c) Cognitive Strategies**

Several participants used cognitive strategies such as word association, self-talk and retracing their steps in order to overcome their symptoms of dementia (N=6). Four participants mentioned active attempts to recall information but the strategies used were not specified.

Stan            'I find that if I relive or rethink my journey I can sort it out quickly so it doesn't effect me any more than that'.

**(d) Hopeful Waiting**

Half of the participants described passively awaiting the recall of forgotten material, the dissolution of confusion or for others to provide a solution (N=5).

David           'I just sort of sit around or stand around for a few minutes and its comes back to me'.

### **3.4.3. Negative Self-Perceptions**

Three categories emerged from the data.

#### **(a) Personal Attributes**

Three participants mentioned negative personal traits corresponding to their symptoms of dementia, which included appearance, confidence, perceiving self as a 'nuisance' and 'not belonging'.

Dorothy        'I thought I looked so awful.....Well, I think I just felt that I am bound not to look the same as gradually it will get worse....I feel that I must look so different... I think my clothes look funny or my hair looks funny'.

#### **(b) Intellectual Abilities**

Half of the participants described the impact of their symptoms of dementia on their perception of their intellectual ability such as feeling 'stupid' and 'useless' (N=5). One participant described his awareness of these difficulties during social interactions.

Charles:        'It seemed to affect my intelligence because I couldn't pick things up'

#### **(c) Ageing**

One participant described how each of the symptoms of dementia described triggered feelings about ageing.

Anne            'It just makes me feel as though I am getting old. I know that I am getting old because I look at the photo up there and I don't look a bit like that now do I?'

### **3.5. Other people's reactions to the participants' symptoms of dementia and the participants' counter-responses.**

This section has been separated into two parts. The first is concerned with other people's reactions to the participants' symptoms of dementia. Two super-ordinate categories emerged from the data, which are the various reactions exhibited by others and the participants' beliefs about others' reactions. The two conceptual categories and corresponding themes are illustrated in Table 5 and discussed below.

The second part is concerned with the participants' counter-responses to others' reactions. Three super-ordinate categories emerged from the data, which are the participants' immediate reactions, management strategies and self-perceptions in relation to these experiences. The three conceptual categories and corresponding themes are also illustrated in Table 5, and are described below. See appendix 18 for the full range of responses provided by participants within each theme.

Table 5: The number of participants who mentioned each theme concerning other people's reactions to the participant's symptoms of dementia.

Categories	Themes	No. of Participants
<b>Part 1: Other people's reactions to the symptoms of dementia</b>		
<b>Reactions</b>	Informing participants about their symptoms	6
	Externalised Emotional Reactions	4
	Assistance	2
	Withdrawal	1
	Responses to participants' counter-responses	1
<b>Participants' beliefs about others' reactions</b>	Positive Reactions	1
	Negative Reactions	3
	Negative attributions about participants	2
<b>Part 2: Participants' counter responses to other people's reactions</b>		
<b>Immediate Reactions</b>	Negative Emotional	5
	Justification of others' reactions	2
	Denial	2
	Social withdrawal and avoidance	1
<b>Management Strategies</b>	Various solutions	6
<b>Self-Perceptions</b>	Negative personal attributes	1
	Negative intellectual abilities	3
	Loss of skills	1

**Part 1. Other people's reactions to the participants' symptoms of dementia.**

Five themes emerged from the data.

**3.5.1. Others' Reactions**

**(a) Informing participants about their symptoms**

Several participants noted that other people informed them of their symptoms of dementia (N=6).

Anne            ‘She will say “You have already told me that”. She points it out. She points out lots of things to me’.



**(b) Externalised Emotional Reactions**

A few participants described others' externalised emotional reactions such as verbal aggression in the form of shouting and teasing and negative facial expressions (N=4).

Margaret      'As I say she [niece] shouts which is not the best way of communicating with somebody'.

**(c) Assistance**

Two participants described other peoples' attempts to provide assistance either through their management of the symptoms of dementia or by providing the participant with suggestions. One participant described how her daughters changed the subject when they recognised her difficulty maintaining the conversation.

Dorothy      'Well the girls [daughters] usually when they hear me stuttering and stammering the girls know that that is a signal to try and change over'.

**(d) Withdrawal**

One participant described her perception of the withdrawal of a neighbour from her life.

Rose          '..she used to come round quite a lot but I never see her....She used to bring the children over'.

**(e) Others' Reactions to the Participants' Counter-Responses.**

One participant described how other people respond to her strategy of social withdrawal, which she employed to cope and manage her symptoms of dementia.

Rose            ‘My daughter rang me up the next day and said “Why did you fly off mum?”’

### **3.5.2. Participants' beliefs about other people's reactions to their symptoms of dementia.**

Three sets of beliefs were described.

#### **(a) Positive Reactions**

One participant described the development of other peoples' realisation and understanding regarding her symptoms of dementia.

June    ‘I think they [other people] are starting to understand....They don't say anything. They understand you see’.

#### **(b) Negative Reactions**

A few participants mentioned their belief that other people experienced negative emotional reactions as a consequence of their symptoms of dementia (N=3).

Dorothy        ‘I am sure that I repeat myself until everybody is absolutely....gone to the wall.’

#### **(c) Perceived Negative Attributions about the Participants.**

Two participants believed that other people would hold negative attributions about them.

One participant described at length what she considered others' beliefs about her to be, based upon their reactions to her symptoms of dementia.

Rose            'And whoever you are talking to you suddenly see that they are looking at you as if to say "What the hell are you talking about?"'.

**Part 2: Participants' counter-responses to other peoples' reactions to their symptoms of dementia.**

Participants mentioned two types of initial responses.

**3.5.3. Immediate Reactions**

**(a) Negative Emotions**

Half of the participants described a variety of negative emotions ranging from annoyance, embarrassment, sadness and anxiety (N=5).

Donald            'Well it annoys me because I know I shouldn't do it'

Rose            '...it's a fear, a fear of rejection.'

**(b) Justification of other's reactions**

Two participants justified and excused other peoples' reactions to their symptoms of dementia.

Margaret            'After all, you expect to tell people something once and only once.

**(c) Denial**

Two participants appeared to show some denial of their difficulties by dismissing the problem and displacing responsibility onto others. The following example illustrates how

a participant displaced the responsibility for her social withdrawal onto her husband and the limited living space within her daughter's home.

Rose            'But Harry wanted to come home because he didn't want to drive home in the dark.....We couldn't have stayed. I mean, she only lives in a little town house. Where would we have slept for a start?'

#### **(d) Social withdrawal & Avoidance**

One participant described her desire to withdraw from social situations as a result of other peoples' reactions.

Rose            'That is why I sort of feel that I don't really want to meet people and don't want to go out and I don't want to make contact with anyone.'

#### **3.5.4. Management Strategies**

Participants described diverse management strategies (N=6). These were, making family decisions about how to manage the symptoms, using visual prompts, requesting that others cease their undesirable interactions, ignoring others' responses, apologising for and admitting problems.

Dorothy        'We [the family] are thinking at the moment what we can do and what is the best way to handle this'.

Charles        'I tell her not to shout at me'.

### **3.5.5. Participants' Self-Perceptions**

Three categories concerning negative self-perceptions emerged from the data.

#### **(a) Negative personal attributes**

One participant mentioned various negative attributes, which included her lack of confidence, perceiving herself as a 'nuisance' and no longer belonging.

Rose            'I just feel that I am a pain in the arse to be honest'.

#### **(b) Negative intellectual abilities**

Three participants mentioned feeling 'stupid' and other related expressions.

Donald        'It just shows that I am a bit more stupid'

#### **(c) Loss of Skills**

One participant's negative self-perception related to her loss of skills.

Rose            'It made me feel that I had lost another skill'.

### **3.6. Participants' reactions to the cessation of social roles, activities & chores.**

Five of the ten participants provided detailed accounts associated with the cessation of social roles, activities and interests. These have been separated into two categories. The first is concerned with social interaction and hobbies and interests and the second, is concerned with their chores and duties. Only those activities which occurred within a social context, will be discussed here. The independent activities will not be included.

Furthermore, driving was not only identified as a lost activity but its removal further impacted upon social activities such as holidays and daily chores.

Donald            ‘Going shopping, going to the doctor. We have to get taxis.....We have a caravan. We used to go down there more when I could drive. Driving had an impact on everything’

The conceptual categories and corresponding themes are illustrated in Table 6. See appendix 19 for the full range of responses provided by participants within each theme.

Table 6: The number of participants who mentioned each theme concerned with the demise of their social activities, interests and chores.

Category	Theme	No. of Participants
<b>Hobbies &amp; Interests</b>		
<b>Emotional Reactions</b>	Positive	2
	Negative	5
	Not meeting others' needs	1
<b>Self-Perceptions</b>	Positive	1
	Negative	2
<b>Chores</b>		
<b>Emotional Reactions</b>	Positive emotions	2
	Positive emotions regarding others	1
	Negative emotions regarding others	1
<b>Self -Perceptions</b>	Negative	3

**3.6.1. Participants' recognition of the demise of social activities, hobbies and interests as a consequence of dementia .**

With respect to ‘social interactions’, three participants described how the symptoms of dementia impacted upon their ability to interact and thus develop and/or maintain relationships.

Margaret        'I realise that I find great difficulty in getting to know people. Much more difficulty than in the past because one can't remember anything, even if you capture some impression, you can't remember it you see.'

Participants mentioned a variety of hobbies and interests that had ceased. These included writing letters, attending the theatre, playing golf, mending things, walking, attending church and engaging in activities with other family members, such as watching their grandchildren play sport.

Dorothy        '...then I suddenly discovered before Christmas that I couldn't .....wasn't writing. I rather used to pride myself on letters.

### **3.6.2. Emotional Reactions**

Three categories of emotional reactions to the demise of such activities emerged.

#### **(a) Positive**

Two diverse positive emotions emerged (N=2). One person described feeling relieved about not having to socialise, while the other described his maintained interest in sport, despite being unable to participate or watch his grandchildren.

Dorothy        'In a way it's a relief....that I haven't got to worry....feeling that nobody will be coming to go out and meet me or anything like that.'

**(b) Negative**

A variety of negative emotions regarding the cessation of activities emerged. These ranged from feeling restricted, the associated loss and pain and the awfulness and disappointment (N=5).

Stan                'It is difficult, hard to accept sometimes, if you have got to lay things aside  
and stop doing it.'

**(c) Not meeting others' needs**

One participant described a number of negative emotions, which concerned others. She expressed feelings of unfairness that her husband was no longer accompanied to activities. What was previously the participant's interest in writing became a task or chore for her spouse. Therefore the participant expressed concern about burdening her spouse and about his ability to adequately undertake such tasks.

Dorothy           'It is very bad luck for [husband] ...just the fact that I can't go with him to  
the theatre. Be with him at the same time.'

**3.6.1.2. Self Perceptions**

Two categories emerged from the data concerned with self-perceptions in relation to the loss of activities.



**(a) Positive**

One participant described how, despite enforced resigning from specific activities at his local church, he could continue to work well with the younger people who attended and felt respected by them.

Stan            'But we work alright with the younger people [church attendees]. They respect us.'

**(b) Negative**

Two participants described negative self-perceptions. These were concerned with 'getting in the way' and being too old to maintain such activities.

Stan            'I am beginning to realise that I am of the past generation and it is a bit old fashioned and slow.'

**3.6.2 Participants' recognition of the demise of their social roles and chores.**

Participants mentioned the cessation of, or delegation of, domestic chores and household management such as paying bills and assisting others (N=3).

Anne            'She does all the phoning for me.....I mean, when I get any letters now I stick them in the front here and when [Friend] comes in she says 'I see you have plenty of letters for me.'

### **3.6.2.1. Emotional Reactions**

Three categories of emotional reactions emerged in relation to the cessation of chores and duties.

#### **(a) Positive Emotions**

Participants described feelings of pleasure and relief in response to resigning from such activities (N=2).

Margaret      'I am very pleased to accept her help. I am only too glad to give them up. I don't want more than I have to do.'

#### **(b) Positive Emotions Regarding Others.**

One participant described the trust he placed in his son to adequately undertake the tasks delegated to him.

Donald      'I trust him completely...If it goes wrong [son] will get us out of trouble'

#### **(c) Negative Emotions Regarding Others.**

One participant described concern about his spouse's ability to adequately undertake the tasks delegated to her.

Donald      'I just hope she understands what she is doing'

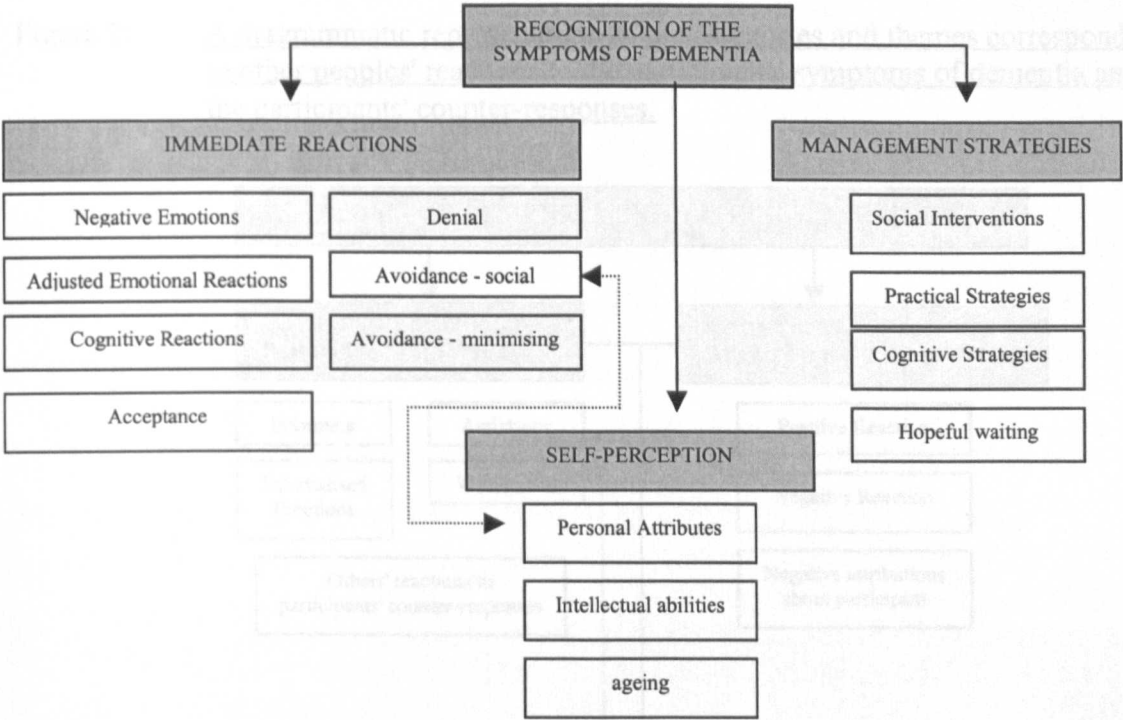
### **3.6.2.2. Self-Perceptions**

Participants described feeling 'incapable' and of no use to others (N=3)

Rose      'Well, I can't drive, so maybe I wouldn't' be much use to Claire.

3.7. Three diagrammatic representations of the research findings.

Figure 1: A diagrammatic representation of the categories and themes corresponding to the participants' reactions to the recognition of their symptoms of dementia.



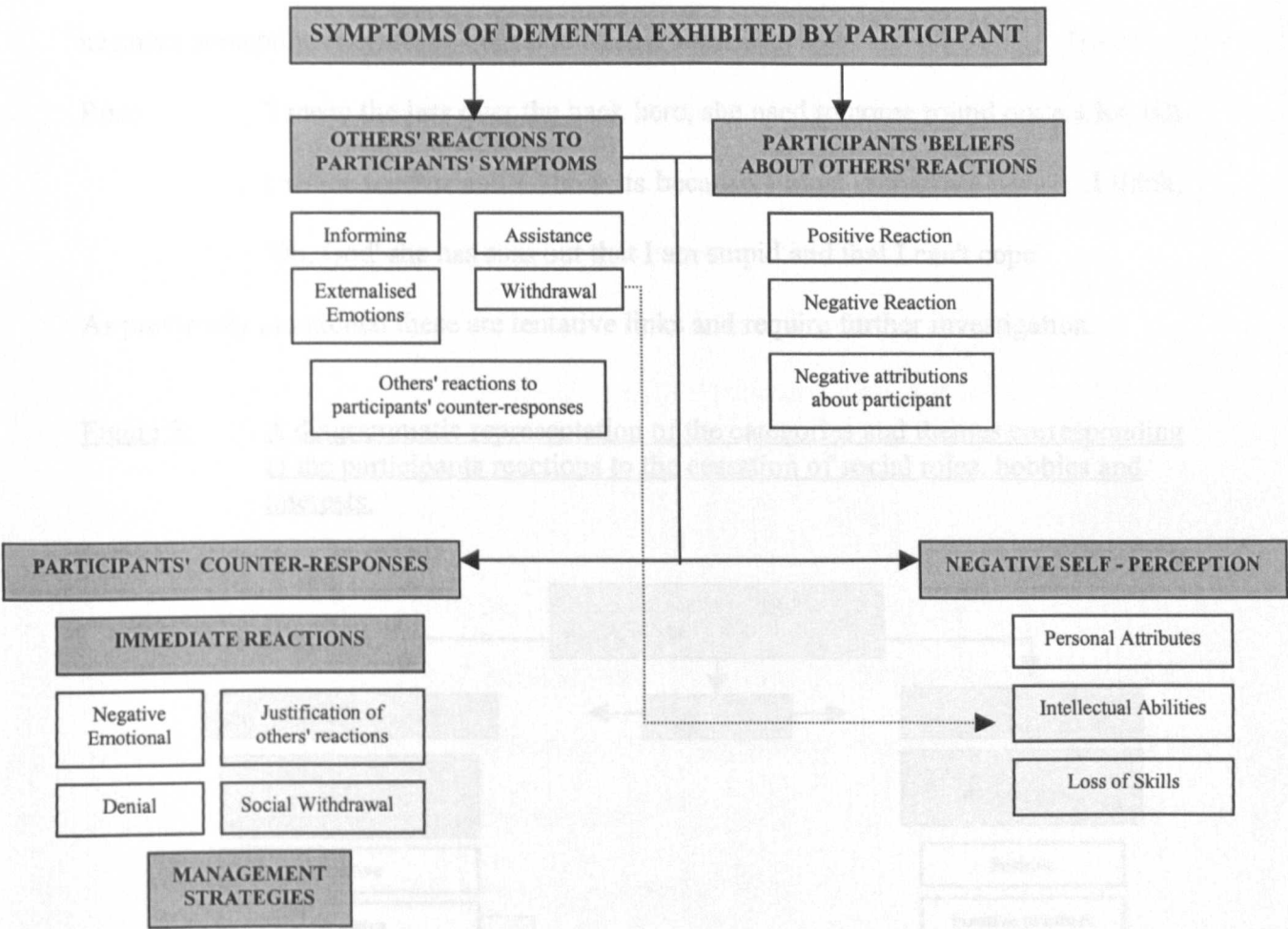
The arrows represent the direct links, suggested by the data, between memory problems and the three super-ordinate categories. Although the data have been organised and presented in terms of these three categories, participant descriptions indicated that these were not distinct and independent but interrelated. Several tentative links between themes both within and between categories were described. One link suggested was between social avoidance and negative personal attributes. This link has been illustrated above and described below.

Dorothy 'At Christmas time when there were parties, I didn't want to go because I thought that I looked too awful'

Rose            'But, you cut off, I don't know....Well, cause you don't feel that you belong.'

As mentioned, these links are tentative and need to be investigated further.

Figure 2:        A diagrammatic representation of the categories and themes corresponding to other peoples' reactions to the participants' symptoms of dementia and the participants' counter-responses.



As in figure one, the arrows represent the direct links between categories as suggested by the data. The symptoms of dementia were directly linked to, other peoples' reactions and the participants' beliefs about other people's reactions. There were also direct links

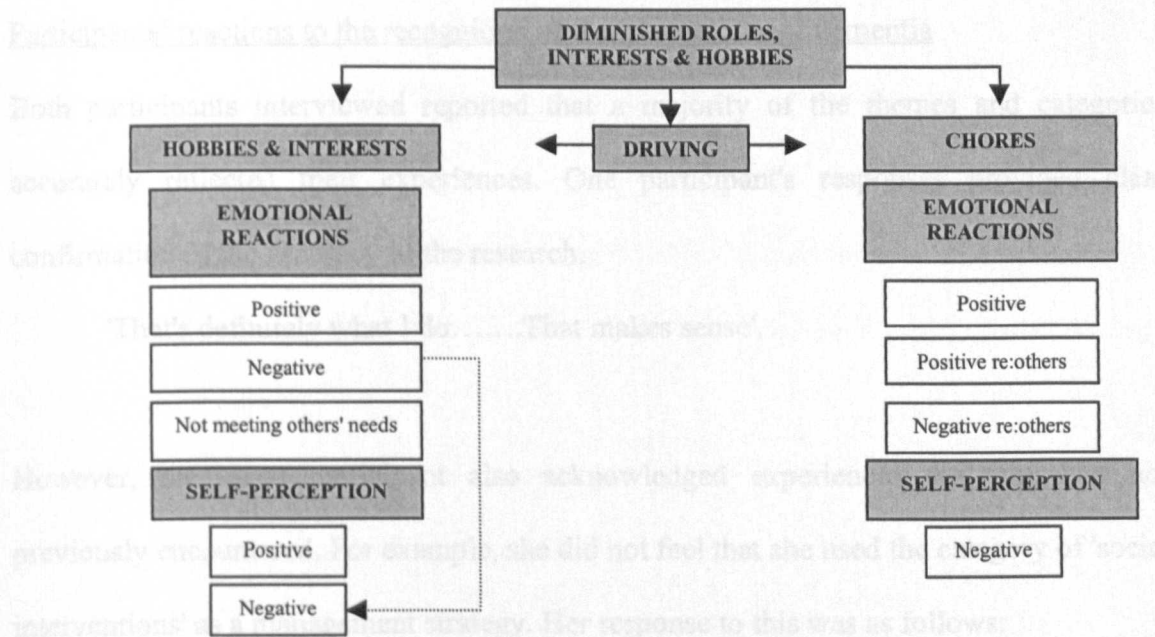
between other people's reactions and two categories, the participants' counter-responses and negative self-perceptions.

As in Figure One, the data were organised into distinct categories, but the categories were interrelated. Several tentative links between themes both within and between categories were described. One link emerged between the others' withdrawal and the participant's negative perceptions regarding their intellectual abilities.

Rose            'I mean the lass over the back here, she used to come round quite a lot, but I never see her and I know its because I must embarrass her.....I think, 'Oh, God' she has suss out that I am stupid and that I can't cope'

As previously mentioned these are tentative links and require further investigation.

**Figure 3:**     A diagrammatic representation of the categories and themes corresponding to the participants reactions to the cessation of social roles, hobbies and interests.



The direct links illustrated in this model are between driving and the loss of interests, hobbies and chores. This was discussed in more detail earlier in this section. Tentative links were also emerged between categories. For example, a link was proposed between negative self-perceptions and negative emotional reactions. The example provided was the loss of activities at church.

Stan                We are too old now. I am beginning to realise that I am of the past generation and it is a bit old fashioned and slow....It is difficult, hard to accept sometimes if you have got to lay things aside or stop doing it.

### **3.8. A Summary of the Results of the Respondent Validity Study.**

Both participants that were interviewed agreed with a majority of the themes and categories that were generated. A summary of the comments provided by the participants is given below.

#### **Participants' reactions to the recognition of their symptoms of dementia**

Both participants interviewed reported that a majority of the themes and categories accurately reflected their experiences. One participant's responses provided clear confirmation of the accuracy of the research.

'That's definitely what I do.....That makes sense'.

However, the same participant also acknowledged experiences that she had not previously encountered. For example, she did not feel that she used the category of 'social interventions' as a management strategy. Her response to this was as follows:

'I couldn't say that I am as good as all that. I cut off'

Her responses remained consistent across time as she reported the same experiences during the validity study as she had done during the previous interview.

The categories generated reflect the diversity of responses provided by all ten participants. It would be contradictory if the respondents agreed with all the categories. For example, one category is labelled 'acceptance' whereas another is labelled 'not wanting to accept'.

Other peoples' reactions to the participants' symptoms of dementia and the participants' counter-responses.

Both participants agreed with the themes and categories generated. The following description reflected a confidence in the confirmation provided by the participant regarding the accuracy of the research.

'Very, very true - You've hit the nail on the head'

Discussing the categories and themes prompted further discussion and exploration of the issues. For example, when the category of social withdrawal was mentioned one participant explained:

'Yes, I don't see people anymore, Peter [friend] is the only person that sees me now. I don't see any of my friends'.

He continued by considering the reasons why people no longer visit.

Participants' reactions to the cessation of social roles, hobbies and interests.

Both participants again confirmed that the categories and themes generated were an accurate reflection of their experiences. This was reflected in a discussion concerned with the cessation of driving:

'I miss my independence. One of the worst things is not being independent. You have to get other people to take you around'.



## **4. Discussion**

### **4.1 Overview**

The research findings will be discussed in relation to 1) existing research literature, 2) design and methodological issues, 3) clinical implications and 4) future research.

### **4.2 Research Findings**

In the following section the findings will be compared with the existing research literature. The section will begin by considering emergent issues concerned with interviewing people with dementia and the diversity of responses obtained, before discussing each of the research questions in turn.

#### **4.2.1. Interviewing people with dementia.**

Goldsmith (1996) referred to the perception that dementia renders self-reflection and expression rarely possible. The findings from this study conflict with this view. The ten participants in this study engaged in a one-hour interview and provided lengthy and detailed accounts. Most participants were articulate and reflective as demonstrated in the extracts of interviews provided in the results section and Appendices 17-19. For those whose cognitive abilities were compounded by their dementia, obtaining meaningful information was facilitated through the structure of the interview schedule, such as the introduction of prompts to aid recall.

#### 4.2.2. The diversity and commonality of participant responses.

In general, the ten participants provided a diversity of responses to the interview questions. This may simply illustrate that under the label of dementia there remain unique people with a multitude of individual differences.

Within the general diversity, corresponding responses emerged which could be clustered to produce the themes and categories. The themes and categories were not determined by subgroups, such as dementia type, age, dementia severity or the presence or severity of depression. It could be hypothesised for example, that the five people diagnosed with Alzheimer's disease would display a similar awareness of their symptoms of dementia or describe similar subjective experiences. This was not demonstrated in the findings. One possible explanation for the diversity of responses within this subgroup is the heterogeneity of Alzheimer's disease (Boller et al., 1992). Two reasons suggested for this heterogeneity are that Alzheimer's acts as an umbrella term for 'different pathological processes' or it is a single disease process which produces diverse responses in different people (Kitwood, 1997a).

As mentioned above, the findings suggested that the participants' mental state did not determine the themes and categories elicited from the data. This diversity may reflect the limitations of the assessment tool used. The Mini Mental State Examination (Folstein et al., 1975), provides an estimate of performance at a single point in time and cannot take account of previous educational levels and skills (Kitwood, 1997a). As noted in the methodology, the MMSE was only used for the purpose of screening potential

participants. It is a well-established research tool and was chosen for its brevity and ease of administration. It would not have been practical to have administered more elaborate assessment tools such as the CAMDEX (Roth et al, 1988), which take longer to administer and score. Like the MMSE, the CAMDEX has also to some extent been criticised for its inability to take into account previous levels of functioning (Kitwood, 1997a).

Participant responses were also not determined by the severity of dementia as measured by the GDS-15. Like dementia, the label of depression covers a wide range of symptoms, which has been attributed to the way in which the diagnostic tools have been created (Kitwood, 1997). The diversity of responses may therefore reflect the heterogeneity of this subgroup of people diagnosed with depression.

#### 4.2.3. Participant's recognition of the symptoms of dementia

The findings illustrated that all the participants spontaneously recognised two or more symptoms of dementia. This figure increased to a further four or more symptoms with prompting, with a mean of eight recognised symptoms. These findings support Foley's (1992) declaration that it is an 'unfortunate misconception' that people are viewed as being unaware of their dementia and Balfour's (1995) findings that 'some kind' of awareness is present in people even within the severe range of dementia (p18). Not only did the participant's demonstrate that they had insight into their symptoms of dementia, but some were also able to describe with great clarity their emotional and cognitive reactions, their 'defence mechanisms' and their methods for managing these symptoms.

Furthermore, the research findings demonstrated that some participant's had insight into the impact of their dementia on others and their relationships. These findings clearly do not support the generalised assumption that insight is lost by the time the person reaches the moderate stages of dementia (Allan & Killick, 1998).

The discrepancy between the participants' spontaneous and prompted recognition of symptoms was not attributed to the participant's acquiescence but to difficulties of spontaneous recall in dementia. Acquiescence as the primary reason was ruled out as the participants did not agree unquestioningly with the prompts provided but continued to clearly discriminate between the symptoms they had experienced and those they had not.

It is important to note that the aim of the research was to identify the participants' subjective recognition of their symptoms of dementia and its impact on self-concept and self-esteem and not to measure the extent and accuracy of their awareness and insight. Such investigations would require an objective measure of the person's symptoms of dementia to compare with their subjective experiences in order to measure the discrepancy.

#### 4.2.4. Participants' reactions to their symptoms of dementia

With respect to the participants' reactions to their symptoms of dementia, three categories emerged from data. The participants described 'immediate reactions' to their symptoms of dementia, the 'management strategies' employed and their 'self-perceptions'.

The category of 'immediate reactions' refers to an episode of e.g., forgetting and comprised a diversity of themes. The seven themes identified were 'negative emotions', 'adjusted emotional reactions', 'cognitive reaction', 'denial', 'social avoidance', 'minimising' as a means of avoidance and 'acceptance'. Such diversity may simply reflect the variance of individual experiences. It may also reflect varying stages of individual adjustment to dementia. Adjustment was also alluded to by a few participants who reported recognised changes in their reactions to their dementia cross time. These responses were labelled as 'adjusted emotional reactions'. Therefore the participants' responses were considered in relation to Kubler-Ross's (1969) six-stage model of adjustment to a terminal illness. In particular, the responses provided within the theme of 'negative emotional reactions' could be considered to reflect both the stages of anger and despair. The stage of resignation could be illustrated through the 'social avoidance'. Finally the responses, which contribute to the theme of 'acceptance', could correspond to the stage of adjustment with the same name. One criticism of stage models is that a chronological process does not exist, but that people move in and out of stages at different points in time. This process may contribute to the diversity of responses. These are tentative hypotheses and require further investigation.

The 'negative emotional reactions' described included sadness, worry, anger, and guilt, which correspond with experiences previously reported in the research literature (e.g., McGowen, 1993). Although the participants described emotions such as 'awfulness' and 'strangeness', extremely intense emotions such as 'paralysing fears' (McGowen, 1993), 'deepening despair' and 'giving up' (Balfour, 1995) were not described. These differing

findings may be due to the different methodologies used. McGowen (1993) chose to provide detailed accounts through her writings to clearly illustrate her experiences. The Thematic Apperception Test as used by Balfour (1995) allows the participant to project their inner world onto pictures that are presented to them, which the interviewer later interprets. This process might allow the participant to feel more emotionally distanced from the material. In comparison, a research interview such as the one used in this study requires the participant to talk directly about their experiences and involves a different type of relationship with the interviewer. Participants may be more defended during research interviews or may not wish to admit the intensity of their emotions. It is hypothesised that participants might feel that admittance would render the emotion overpowering or may cause the interviewer to question their integrity and ability to cope. Consequently, participants may have attempted to conceal the severity of their negative emotional reactions during the research interviews. A number of factors such as the sex, age and profession of the interviewer are a few factors which may have influenced the interactions and processes within this relationship.

The category of 'social avoidance' had previously been reported by Balfour (1995), but labelled as 'withdrawal'. In his study, withdrawal appeared to be associated with 'diminished functioning, blame or loss' (p17). Similarly, tentative links were identified in the current study between social withdrawal and negative personal attributes, such as negative appearance and the feeling of not belonging, due to the loss of skills, or social interactions being impeded by memory impairments. Carers have frequently reported the withdrawal of people with dementia and have identified this as a means of stress for

themselves (Green, 1982). For the person with dementia, withdrawal may serve a defensive function by removing them from situations which undermine and challenge their sense of self. One participant described a sense of relief through social withdrawal. However, the losses associated with withdrawal may also place their identity in question. It is hypothesised that this imposed isolation might contribute to the levels of depression within this illness, however, this requires further investigation.

Four types of 'management strategies' employed by the participants to manage their symptoms of dementia were elicited from the data. These were 'social interventions', 'practical strategies', 'cognitive strategies' and 'hopeful waiting'. These strategies may reflect the stage of 'Maximising' described by Keady & Nolan (1994, 1995a), whereby the person uses adaptive coping strategies to cope with losses. McGowen (1993) described her recognition of changes in her behaviour, such as the development of obsessive-compulsive traits to impose a sense of security. Such traits were not specifically described in the current research, however, the management strategies employed may take on the characteristics of an obsessive-compulsive behaviour if they are repeatedly implemented or used excessively.

The impact of the symptoms of dementia, the changes in relationships and the demise of activities on-the person's self-perceptions will be discussed together later in this section.

#### 4.2.5. The effect of dementia on relationships

Some participants demonstrated that they recognised other people's reactions to their symptoms of dementia and developed assumptions about what other people thought about them. Furthermore, some participants described their subsequent counter-responses to these, which consisted of three categories, 'immediate responses', 'management strategies' and 'self-perceptions'. To add a further dimension, one participant also suggested that other people would question her 'immediate reactions' to their symptoms of dementia, such as excusing herself from social situations in which she felt inadequate due to her memory lapses.

The symbolic interactionist model of self-identity (Blumer, 1969) can be applied here to dementia. This model suggests that individuals are reflective and through their interactions form meanings about their environment. This process was demonstrated through the categories elicited. The participants' responses demonstrated that the 'self' remained active as actions and conversations influenced each other through a continuous process of interpretation and re-interpretation. The participants clearly described the presence of a circular process. For example, as mentioned above one participant described how she chose coping strategies according to the social situation, how other people responded to these and how these responses influenced her subsequent reaction.

Two experiences described in the research literature pertaining to relationships were the desire for closeness and comfort (Balfour, 1995) and heightened sexual desire (McGowen, 1993). These were not mentioned in the current research. In this study, some



participants seemed to present positive images of their partners and their relationships. When negative interactions were described these were later retracted or the researcher was informed that the situation had changed for the better. It was hypothesised that these participants may have felt unable to talk about desired interactions that were absent from their relationship or speak negatively about the person who is caring for them, as they should only show their gratitude. They may have experienced anxieties about expressing their feelings and wishes during the interviews due to the potential fear of abandonment (McGowen, 1993).

#### 4.2.6. The effect of dementia on activities

As with their insight into their dementia and its effect on relationships, some participants also recognised those activities which had been maintained, diminished or had been delegated to others. It had been reported that one of the most devastating things to happen to an older person, is the loss of social roles which provide both status and the opportunity to contribute to their social network (Wainwright, 1997). However, the findings demonstrated that some of the participants' reactions seemed dependent upon the type of activity that had ceased. Both positive and negative reactions were described for the cessation of interests and hobbies. The negative reactions were concerned with loss and disappointment. In contrast, the positive reaction was one of 'relief', not about a specific activity but about no longer having to interact and socialise with others. In relation to the demise of chores, no negative reactions emerged from the data. Some participants described only the feeling of happiness about delegating these. However,

there were contrasting feelings such as trust or concern about another person adequately undertaking the chore on behalf of the participant.

#### **4.2.7. The effect of dementia on self-perceptions.**

In line with the research on chronic illness (Charmaz, 1983), the symptoms of dementia were found in this study to have a negative impact on self-perceptions. The data suggested that this occurred through the subjective recognition of the symptoms of dementia, changes in relationships and the demise of activities. Only one person mentioned a positive self-perception, which was feeling respected by younger people within his church. The clinical implication of this findings will be discussed in section 4.4.

### **4.3. Design and Methodological Issues**

The following section will consider the research findings in relation to the design and methodological issues.

#### **4.3.1. Interpretative Phenomenological Analysis and Grounded Theory.**

As described in the introduction, qualitative methodology was considered the most appropriate to investigate the subjective experiences of dementia (see section 1.11). However, the researcher was aware that the semi-structured interview employed imposed greater structure than is recommended by the IPA and grounded theory methodologies. The researcher wanted to ensure that people with dementia could participate in qualitative research and that their experiences could be heard. Therefore, it was necessary to take

account of their cognitive limitations and to facilitate their engagement by structuring the interview schedule accordingly, especially at the start of the interview in relation to the participant's recognition of their symptoms of dementia. In the remainder of the interview the researcher attempted to remain true to the openness of the IPA approach by beginning with broad questions to promote the spontaneous emergence of themes. Prompts were only introduced once the participant had had the opportunity of answering spontaneously. Alternative methodologies were considered. For example, the data could have been analysed using the principles of content analysis (Krippendorff, 1980). However, as research investigating the subjective experiences of dementia was limited, the researcher wished to "capture the richness" of the participants' responses offered by the IPA approach (Smith, 1995, p9) rather than reduce them to pre-specified categories. The researcher believes that much of the richness of the verbatim interview data, illustrated in the results section, would have been lost had an alternative methodology been used.

#### 4.3.2. Recruitment of participants.

The recruitment of participants throughout the duration of the study remained problematic. The most significant factor determining successful recruitment was whether or not the participants had been fully informed of their diagnosis. In section 4.3.3, the reasons for adopting an alternative label and its influence on recruitment are discussed. Recruitment may have further been influenced through the involvement of mental health workers and the measures used which will be discussed below.

The inclusion and exclusion of participants was largely determined by the opinions of mental health workers, which could potentially have influenced the numbers and the characteristics of those recruited. Recruitment bias may have been consciously and unconsciously active during the selection of participants. Discussions with 'Keyworkers' suggested that they may have over interpreted some of the requirements of the research, and nominated only those people who they felt could participate fully in a research interview and who could talk openly about their dementia. Furthermore, participants may have been unnecessarily excluded from the research due to keyworkers' attributions and assumptions about communication and insight in dementia. These may reflect the generalised perceptions which have been reported in the research literature (Goldsmith, 1996). For these reasons the participant sample may not be representative of people with dementia in the mild to moderate range of severity, but may represent those who are more articulate and/or more able to reflect on their predicament.

As previously mentioned, the MMSE (Folstein et al., 1975) provides an estimate of performance at a single point in time. Suitable participants may have been inappropriately excluded from the research based upon the scores documented in the medical files from previous examinations. This further suggests that the group may not be a representative sample.

For the reasons described above and the small number of participants recruited to this research, generalisability of the findings is limited. It is difficult to predict the impact the excluded participants would have had on the findings if they had been interviewed.

Communication difficulties, greater levels of confusion, or lower insight may have emerged. The extent of these difficulties and the usefulness of the interview schedule in facilitating engagement are unknown. Potentially, those people excluded from the research on the basis that they appeared to lack insight into their dementia, may have demonstrated that their insight was largely intact but that this had not been elicited, as they had not previously been asked questions about their experiences.

#### 4.3.3. The use of terminology: Dementia or Memory Problems

As previously mentioned, it was initially the researcher's aim to recruit only those people who had been informed of their diagnosis of dementia. However, it came to the researcher's attention, and reflected previous research findings (McWilliams, 1998) that people with dementia were not always informed of their diagnosis. Furthermore, it seemed that the mental health workers involved with their care were also sometimes unaware of the diagnosis given or how the person spoke about their illness. This raises questions about the opportunities given to people with dementia to discuss their illness whether it is known as 'memory problems' or 'dementia'.

Due to the ethical concerns, such as the potential for premature disclosure, the researcher was advised to only use the term 'memory problems'. Orientating the participants to discuss 'memory problems' instead of dementia may have influenced the content of the spontaneously elicited data. The participants may have felt constrained to discuss only their memory problems and impeded from reflecting upon the full array of symptoms associated with dementia. Attempts were made by the researcher to elicit 'other

problems' that the participants recognised through open questions and later through the prompts provided. However, the extent to which the language used influenced the findings remains uncertain. Interestingly, many of the participants spontaneously mentioned their diagnosis of dementia or Alzheimer's disease during the interview and were aware that this was causing their memory problems. Research investigating the influence of receiving differing explanations for their illnesses and its impact on adjustment should be investigated further.

#### 4.3.4. Measures

The usefulness and the limitations of the MMSE and the GDS-15 have previously been discussed in relation to the diversity of the participants' responses. The potential impact on the recruitment process of using the MMSE as a screening tool was discussed in the previous section.

#### 4.3.5. Evaluation of reliability and validity

The reliability and validity of the study's findings were evaluated using the following criteria.

##### *A. Auditability:*

Auditability was aimed for in a number of ways. Reflective accounts of the research process were kept in the form of a research diary, which can be reviewed by the reader. It contains accounts of the influence of the researcher's frame of reference and subjectivity on the emerging themes and categories. It was important for the researcher to

remain reflective and aware of such influences. For example, in the early stages of analysis, the researcher recognised that their own frames of reference e.g., pre-existing models of coping, were overly influencing the emergence of themes from the data. Consequently, the researcher returned to the primary source material and began the process again. A full transcript has been provided (Appendix 16) together with a complete listing of codes and themes with the corresponding codes (Appendices 17-19). Maintaining the research diary (Appendix 20) and discussing process issues in supervision facilitated a continual process of reflectivity.

#### *B Independent audit:*

Recruiting another person to conduct part of the analysis encourages reflective practice and careful consideration of the process of analysis. There was considerable consensus regarding the themes and categories developed. However, some deviation also occurred with respect to responses such as 'I don't let it worry me' [Charles]. The independent auditor felt that this illustrated the participant's 'acceptance' of their symptoms of dementia, whereas the researcher contemplated whether it reflected his 'denial'. A discussion was held regarding the extent to which the researcher and auditor were imposing their interpretation on the data. Through discussions agreement was reached about whether codes should be re-labelled or combined to form new categories.

#### *C. Respondent Validity:*

Respondent validity was a further method used to assess the validity of the study. Two participants were asked to comment on the analysis of the data and the extent to which it

reflected their experiences. The participants generally agreed with the themes and categories (see section 3.8). However, due to the diversity of the responses elicited, the participants could not have experienced all of the themes generated. For example, their responses would have been contradictory if they agreed with both the categories of 'accepting' and 'not wanting to accept'. However, it is also acknowledged that their experiences might differ according to the symptoms and the context.

The power imbalance between the participant and researcher needs to be considered when undertaking this method of validation. The researcher may be perceived as an 'expert' (Henwood & Pigeon, 1995) and respondents may feel constrained from expressing disagreement. The respondents in this study did not seem to feel constrained to report that some of their experiences differed from those of the other respondents. Furthermore, Bryman (1988) argued that this cannot be an accepted method of validation as participants do not hold a 'privileged status' and are thus unable to comment on the parts of the analysis which do not directly relate to them. The participants in this study perceived this process as a validating experience as it confirmed that other people had similar experiences as themselves and highlighted potentially useful coping strategies that were used by others.

#### *D. Generativity*

This is evaluated by the extent to which the research is clinically informative and generates potential areas of future research. The findings from this research have proved to be substantially generative. They have developed a greater understanding of the



experiences of people with dementia and have illustrated that some people remain insightful and reflective. The clinical implications of these findings will be discussed in the following section. Furthermore, new research questions have been generated by these findings (see section 4.5).

#### *E. Transferability*

Transferability refers to the extent to which the findings can be generalised or transferred to other contexts (Guba and Lincoln, 1989). This was aimed for in a number of ways. The characteristics of the sample were fully described allowing for comparisons with other samples. The limitations of the sample for example, the selection procedures, have been described in this section together with the boundaries for reasonably generalising from the study. Finally, ‘thick descriptions’ were provided so that the reader can assess the potential transferability (see ‘Results’ section) (Miles & Huberman, 1994).

#### **4.4. Implications for Clinical Practice**

The findings of this research have implications for clinical practice. These will be discussed in terms of attributions made about people with dementia, considerations for interviewing people with dementia, individual therapy, working with couples and families, working with organisations and involving people with dementia in service evaluation.

#### 4.4.1. Attributions about people with dementia

These research findings suggest that within all aspect of our work with people with dementia, health professionals should avoid making assumptions and generalisations about their awareness and insight into their dementia, its impact on them and others and their ability to communicate and share their experiences. Generalisations should not be made simply according to the presence of dementia, dementia type, dementia severity or the age of the person. These can act as useful guides when working with people with dementia but should not dictate interactions with them and the care provided. For example, there was variability with the small sample of participants recruited to this study and some of those people scoring low on mental state tests were able to display insight and reflect on their situation. What is required is a person centred, flexible and individualised approach to care, with the central aim of discovering the person, their attributes, abilities and interests alongside their difficulties for which they are obtaining help. Discovering the person, instead of simply viewing them as a patient with dementia should help to maintain their identity and sense of self. The need to assess the positive aspects of people's lives, through biographical interviewing, has been recognised in assessments for long term care (Kivnick, 1991) and community care services (Gearing and Coleman, 1996).

#### 4.4.2. Interacting with people with dementia.

The findings demonstrated that some people with dementia recognise other people's reactions to their symptoms of dementia and develop beliefs about these. It is therefore important to be mindful and respectful during our interactions with people with dementia,

and not to assume that their awareness is lost. Furthermore, investigators have explored how behind everyday speech there lie assumptions and models of aging and how the language that is used may inhibit or restrict older people or even promote their decline (Coupeland, Coupeland & Giles, 1991). The aim is therefore to provide validating interactions, which do not reinforce assumptions and stereotypes. It is suggested that good practice for health workers is to be aware of their own attributions, assumptions and prejudices about ageing and illnesses such as dementia, and how these can be projected onto the client or be acted out within the therapeutic relationship.

The research interviews suggested several practical considerations when talking with people with dementia. Some people with dementia may need additional time to express their thoughts, feelings and experiences and time for these to be heard. Assumptions about an individual's means of communicating should not be assumed but discovered. For example, gaps in conversation could hastily be misinterpreted as a loss of attention, but the person may simply be collecting their thoughts. Attending carefully to conversations which on the surface appear disjointed and irrelevant, may reveal meaningful insights. As Kitwood (1997) recommended, close attention should be paid to 'metaphor and oblique allusion' and verbal and non-verbal registers. Not only does this facilitate communication, but having a voice and being given the opportunity to develop meaningful interactions with others will help to maintain a sense of self. Time is clearly an important factor when communicating with people with dementia, but unfortunately it is often a constraint, particularly within residential care settings where resources are low.

#### 4.4.3. Maintaining identity and individuality

The results indicated that self-perceptions were affected by the person's recognition of their symptoms of dementia, through interactions with others and the demise of activities. Preserving continuity and a coherent sense of self might be facilitated through reminiscence therapy, and encouraging the person to recall their story (Mills & Coleman, 1994). Cheston (1996) suggested that the stories are not only important for maintaining identity but they are also a means of exploring and communicating experiences of dementia. However, he noted that attention may detract from other aspects of the persons talk when there is an over emphasis on the past, and that the 'youthful past' may be implicitly reinforced as of greater value than the 'older present' (p34). It must also be recognised that the past itself can be a source of disturbance (Coleman, 1986) and a reminder of what has been lost or changed. It is therefore recommended that 'life review' counselling is undertaken on an individual basis, sensitively and over a period of time (Haight, Coleman & Lord, 1995). Reviewing a person's story is an individualised therapeutic approach, which will recognise the uniqueness of each person with dementia. Stories and experiences could also be shared within a group format. Similarities in experiences can allow people to feel less alone with their illness and not as 'different' as they had perceived themselves to be.

For the reasons described, it seems appropriate to suggest that people with dementia should be provided with every opportunity to tell their stories, to listen to others' stories and for these to be heard. As the illness progresses the individual will need to rely on others to keep their story alive.

#### 4.4.4. Individual Therapy

As a clinician, it is important not to assume that people with dementia are unable to participate in therapeutic work due to their cognitive impairments. The participants' engagement in the research interviews suggests that some people with dementia could potentially engage in therapeutic work. Research into appropriate therapeutic modalities and outcome needs to be undertaken. This also needs to be explored for people who are perhaps less articulate or who appear to have less insight into their condition.

#### 4.4.5. Working with couples and families.

The findings provided support for the suggestion that self-concept is influenced through relationships. Some participants described other people's reactions to their symptoms of dementia, their beliefs about how they are perceived, and their counter reactions to these. Using a systemic approach partners and families could discuss interactions which they perceive to be helpful and unhelpful. They may develop strategies for managing the symptoms of dementia, which may include rules about whether or not it is helpful for a family member to intervene. The person with dementia could also undertake reality testing by checking out their beliefs about how they are perceived by others.

When conducting any form of therapeutic work with people with dementia modifications may need to be made to the therapeutic session. For example, they may need to be shorter, as the client may not be able to sustain attention for as long as an hour. Alternatively, a break in the session may be helpful. Due to memory impairments clients may forget the content of the sessions. A written summary of the session can act as a

prompt to aid recall and to maintain continuity. Simple language structures should be employed. However, the therapist should be mindful of language that could appear patronising.

#### 4.4.6. Working with Organisations.

The research has highlighted the need to avoid making generalisations about people with dementia. In order to preserve individuality and a positive self-concept, mental health workers should remain aware of the communications and interactions with people with dementia. Kitwood (1990) described the 'malignant social psychology' which signifies a care environment, which is damaging to 'personhood'. The term 'malignant' does not suggest that caregivers have evil intent but it reflects the 'cultural inheritance'. Seventeen types of interactions were identified within these care settings. These include disempowerment, infantilisation, labelling, banishment and disparagement. An observational method developed by Kitwood and Bredin (1992) to assess such interactions in care settings is Dementia Care Mapping. Once a 'malignant social psychology' is identified, a series of short training sessions can be implemented with care staff, which have been found to greatly reduce the negative interactions (Kitwood, 1997).

The role of the Clinical Psychologist includes disseminating information to other mental health workers and residential care staff through organised teaching and consultation. Through this role, psychologists can help to dispel myths and misconceptions about people with dementia, and can promote positive working relationships, which take

account of the unique person behind the dementia, which in turn helps, it is hypothesised, to maintain identity.

#### 4.4.7. Interests versus chores.

Some participants reported different reactions to the demise of interests and chores. Diminished involvement in pleasant activities resulted in feelings of loss and disappointment, while the participants seemed pleased to delegate chores. These findings are not surprising when one considers that hobbies and interests as chosen activities are individualistic and can be seen as reflecting the personality and skills of the individual. These seem more associated with a unique sense of self when compared to chores, which are often imposed and undertaken by the general population. Hobbies and interests are chosen for their enjoyment and do not necessarily involve achieving a specific goal, for example, enjoying country walks. Chores on the other hand involve the completion of specific tasks and may therefore serve to continually remind the person of their failing abilities. Clinical practice suggests that people are often encouraged to maintain household chores. However, the present results suggest that it may be more appropriate to encourage the maintenance of interests and hobbies as far as possible. However, it is also important to recognise that several people mentioned the need to withdraw from activities involving social interactions as these elicited strong reactions and a negative sense of self. Therefore maintaining chosen activities that do not have a social component would seem to be of most benefit. It is, however, important not to generalise these findings. Although it was not found in this study, for some people chores may have a stronger influence on

people's identity than interests, as these may reinforce societal roles, as for example, a mother, grandmother or carer.

The results revealed that some participants were also concerned that their social withdrawal reduced their partner's involvement in social events and interests. Encouraging informal carers of people with dementia to maintain their own interests should not only provide them with respite from the caring environment, and allow the carers to maintain their own identity through their interests, but could also alleviate concern and guilt in the cared for person. This seems potentially beneficial to both parties.

#### 4.4.8. Service Evaluation

Maintaining generalisations about people with dementia may potentially serve to exclude them from service related projects and evaluations, which prevents them from sharing their views about their care and service planning. Such exclusion has implications in the light of the recent NHS reforms, through which there has been a developing awareness of the importance of consumer participation in 'effective service planning and delivery (Lowe, 1992). Sheilds (1985) proposed three reasons for accessing the views of mentally ill patients, which can also be applied to people with dementia. First, to investigate the effectiveness of treatments from the patient's perspective, which can be used in conjunction with corresponding evaluations. Second, to identify potential areas of service improvements aimed to 'make their lives more tolerable' and third, to increase consumer



participation, thus, reducing the barriers between patients and health professionals (Spencer, 1996).

A ten year modernisation programme has been proposed through the recent reforms (A first Class Service (DOH, 1997). The Government intends to guarantee clear national standards of service that will be set through National Service Frameworks and through a National Institute of Clinical Excellence and delivered locally through a 'new system of clinical governance'. One such method for measuring standards is a national survey of patient and user experiences of the NHS and clinical quality, conducted and published annually. It is important that where possible, people with dementia are provided with the same opportunities as other client populations to share their views. Current methods of obtaining such information may need to be adapted for this purpose.

#### **4.5 Future Research**

It is important that further research is conducted into the subjective experiences of people with dementia as only limited research is currently available. Further research is also important to insure that we are implementing evidence-based practices and not basing our practices on misguided assumptions.

As noted in the introduction, research concerned with identifying the awareness in people with dementia is scarce. Such information would have direct implications for their involvement in and decision making about their care, service planning and delivery and

the future. At present, the research suggests that people are assumed to be unaware of their dementia, but this has not been supported by the current findings.

Several themes spontaneously emerged during the research interviews, which were not concerned with the research questions posed by this study, but which should be considered for future research. The first concerned anxieties about the future. The themes that emerged included the fear of further deterioration, leading to dependency, moving to residential accommodation, the loss of a spouse and the effects of their own death on a spouse and views about euthanasia.

Several participants spoke of their experiences of receiving the diagnosis of dementia. Participants could provide us with invaluable information about this experience at a time when there is a debate about whether or not people should be informed of their diagnosis.

The inclusion criteria necessarily lead to the exclusion of participants for whom English was not their first language. Future research should investigate differing cultural groups in relation to the effects of the symptoms of dementia on their sense of self. In particular, it would be interesting to investigate whether differing illness perceptions influenced these experiences.

#### **4.6. Conclusion**

The findings demonstrated that the participants in this study recognised their symptoms of dementia. Furthermore some participants indicated that their illness had effected them, their relationships and their activities in a number of ways, which appears to have had a further negative impact on self- perceptions.

Although the generalisability of the findings is limited, they remain important as they have challenged the generalised assumptions about people with dementia. They demonstrated that some people in the mild to moderate stages of dementia do have insight into their illness, are reflective and articulate and can talk in detail about their experiences. Furthermore, important insights into conducting research with people with dementia have be gained and can be disseminated for future research.

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## **Appendices**

- Appendix 1:** Letter from the Local Research Ethics Committees Granting Ethical Approval to undertake the research within service one.
- Appendix 2:** Letter from the Local Research Ethics Committees Granting Ethical Approval to undertake the research within service two.
- Appendix 3:** Letter from the Local Research Ethics Committees Granting Ethical Approval to undertake the research within service three.
- Appendix 4:** Information Sheet
- Appendix 5:** Participant consent form 1:  
Consent for the researcher to contact participant
- Appendix 6:** Participant consent form 2:  
Consent to participate in the brief assessment and to complete the depression questionnaire.
- Appendix 7:** Participant consent form 3:  
Consent to participate in the semi-structured interview.
- Appendix 8:** Letter to 'Keyworkers' and Keyworker Questionnaire.
- Appendix 9:** Summary Sheet for Keyworkers
- Appendix 10:** Letter to participants from services one, three and four, inviting them to participate in the research.
- Appendix 11:** Letter to participants from service two inviting them to participate in the research.
- Appendix 12:** Letter to the carers of participants from service two.
- Appendix 13:** Mini-Mental State Examination (MMSE) (Folstein et al, 1975)
- Appendix 14:** Geriatric Depression Scale 15 (GDS-15)
- Appendix 15:** Semi-structured interview
- Appendix 16:** Full interview transcript with identified codes for participant 6

- Appendix 17:** 'Participants responses to their recognition of their symptoms of Dementia'. The full range of responses provided by participants
- Appendix 18:** 'Other people's reactions to the participants symptoms of dementia and the participants counter-responses'. The full range of responses provided by participants.
- Appendix 19:** 'Participants' reactions to the cessation of social roles, activities and interests'. The full range of responses provided by participants.
- Appendix 20:** Summary of the Research Diary

23 December 1998

Telephone:

Fax:

Psychologist in Clinical Training  
South Thames Clinical Psychology Training Scheme  
Salomons Centre, David Salomons Estate  
Broomhill Road  
Southborough  
Tunbridge Wells TN3 0TG

Dear

**Re: An investigation of the self-concept of older adults with dementia - 98.06.12**

The Local Research Ethics Committee of 16 December 1998 considered the application for the above named study and based on the information provided gave approval for the study to proceed.

Yours sincerely

**Chairman  
Local Research Ethics Committee**

**Please Note:** All research should be conducted in accordance with the guidelines of the Ethical Committee and the Committee should be informed:

- (a) when the project is complete.
- (b) what stage the project is at one year from today's date.
- (c) if any alterations are made to the treatment or protocol which might have affected ethical approval being granted.
- (d) all investigators whose projects have been approved by this Committee are required to report at once any adverse experience affecting subjects in the study.

Incorporating:

## **ETHICAL COMMITTEE (RESEARCH)**

24 September, 1999

Dept of Psychology

Dear

**Re: A Qualitative Investigation of the Self-Concept of Older Adults with dementia (159/99)**

The Ethical Committee (Research) considered and approved the above study at its meeting on 17 September 1999.

Initial approval is given for one year. This will be extended automatically only on completion of annual progress reports on the study when requested by the EC(R). Please note that as Principal Investigator you are responsible for ensuring these reports are sent to us.

Please note that projects which have not commenced within two years of original approval must be re-submitted to the EC(R).

Please let me know if you would like to nominate a specific contact person for future correspondence about this study.

Any serious adverse events which occur in connection with this study should be reported to the Committee using the attached form.

Please quote Study No. 159/99 in all future correspondence.

Yours sincerely,

Research Ethics Coordinator

Direct Line:

Our Ref:

Tel  
Fax  
Minicom

Clinical Psychology Training Scheme  
Salomons  
Centre for Applied Social and Psychological Development  
David Salomons Estate  
Broomhill Road  
Southborough  
Tunbridge Wells  
Kent TN3 0TG

Dear

Our Protocol No. (Please quote in all correspondence)  
A Qualitative Investigation of the Self Concept of Older Adults with Dementia

At its meeting on 14 Junem, 2000 the Local Research Ethics Committee ratified my  
Chairman's Action in granting ethical approval for the above study as detailed in my letter of  
17 May, 2000.

Yours sincerely,

Chairman - Local Research Ethics Committee



INVESTOR IN PEOPLE

Chairman:

Chief Executive:

**Information Sheet for People Being Invited to Participate**  
**in a Research Project**

You are invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends, relatives and your GP if you wish. Ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

**Your Questions Answered:**

**Q. What is the purpose of the study?**

The purpose of the study is to investigate the experiences of people with memory problems. In particular, the research aims to explore the effect of memory on your daily life and relations with others. The research will be conducted over two meetings both lasting for approximately one to one and half hours.

**Q. Why have I been chosen?**

Approximately ten people with memory problems will be recruited to this study. All participants will be identified through their contact with their local Community Mental Health Teams for Older Adults and will be people whose first language is English.

**Q. Do I have to take part in this research?**

Your participation in this research is voluntary. You are free to withdraw from this study at any time, without having to give a reason for doing so. If you do not wish to take part, or if you withdraw from the research at a later date, this will not affect the services, which you receive now or in the future.



**Q. What will I be asked to do?**

If you are interested in participating in this research, you will be asked to sign the consent form enclosed. I will then telephone you to arrange a time to visit you at home. During this meeting, you will be asked to undertake a brief assessment and a short questionnaire. The assessment may be familiar to you as it is used routinely within services. I may then ask to interview you on a separate occasion for approximately one to one and a half hours. I will ask you questions about the effect of memory problems on your daily life and relations with others.

**Q. What are the potential benefits of taking part?**

It is hoped that this research will contribute to the understanding of health workers about the actual experiences of people with memory problems. Consequently, it is hoped that this greater understanding will be beneficial to the development of services for people with memory problems and their families.

**Q. What happens to the information that I give?**

All information which is collected about you during the course of the research will be kept strictly confidential. If as a result of taking part in this research you become distressed or may need to talk to someone I will inform you of the person you should contact.

The interviews will be numbered so that your name is not used, to ensure that the information you provide remains anonymous. As it is not possible for the consent forms to be anonymous these will be stored separately from the other information to maintain your confidentiality. I am required to notify your GP of your participation in this research.

A final report of the research will be written and will be available from September 2000. Your name will not appear in this report and I will ensure that you cannot be identified through any information used.

With your permission I would like to tape-record the interview so that I will have an accurate record of our discussion. The tapes will be securely stored in a locked cupboard and will be erased on completion of the research. If you choose to withdraw from the research any information provided can be destroyed and not used in the final report if you so wish.

**Q. How do I contact you if I have further questions?**

Please do not hesitate to contact me if you have any further questions regarding this research on (*Researcher's Number*)

Thank you very much for taking the time to read this information sheet.

**Psychologist in Clinical Training**

Investigating the Experience of Memory Problems

Participant Consent Form 1

I have read or have been read the information sheet provided regarding the research project, which aims to investigate the experiences of people with memory problems.

I understand that I will be asked to participate in a brief assessment and will complete a short questionnaire. I may then be interviewed on a separate occasion about my experiences of memory problems. I give my permission to be contacted so that an appointment can be arranged.

I also understand that I am free to withdraw my consent to participate in this study at any time without having to give a reason. Withdrawal from the study will not effect the services that I receive now or in the future.

I hereby fully and freely consent to participate in this research project and to be contacted so that an appointment can be made for my participation in this research project.

Signed (Participant) .....

Name (Block Capitals) .....

Date .....

Telephone Number .....

If you do not wish to participate in this research please could you sign and return the form below.

I do not give my consent to be contacted to participate in the research project, which aims to investigate the experiences of people with memory problems.

Signed .....

Name (Block Capitals) .....

Date .....

Investigating the Experience of Memory Problems

Participant Consent Form 2

I have read or have been read the information provided regarding the research project, which aims to investigate the experiences of people with memory problems. I have enough information about the research project.

I understand that I will be asked to participate in a brief assessment and to complete a short questionnaire. I may then be asked to participate in an interview at a later date.

I also understand that I am free to withdraw my consent to participate in this study at any time, without having to give a reason. Withdrawal from the study will not affect the services that I receive now or in the future.

I hereby fully and freely consent to participate in this research project.

Signed (Participant) .....

Name (Block Capitals) .....

Date .....

I confirm that I have explained the nature and procedure of the research to the participant and their rights within this research. The participant has given their consent freely and voluntarily.

Signed (Researcher) .....

Date .....

Investigating the Experience of Memory Problems

Participant Consent Form 3

I have read or have been read the information provided regarding the research project, which aims to investigate the experiences of people with memory problems. I have enough information about the research project.

I understand that I will be interviewed about my experiences of memory problems. I also understand that I am free to withdraw my consent to participate in this study at any time, without having to give a reason. Withdrawal from the study will not affect the services that I receive now or in the future.

I give/do not give\* consent for the interview to be tape-recorded.  
(\*Delete as applicable)

I hereby fully and freely consent to participate in this research project.

Signed (Participant) .....

Name (Block Capitals) .....

Date .....

I confirm that I have explained the nature and procedure of the research to the participant and their rights within this research. The participant has given their consent freely and voluntarily.

Signed (Researcher) .....

Date .....

(Name & Address)

(Date)

Dear (Colleague),

I am conducting the following research for my Doctorate in Clinical Psychology:

**'A qualitative investigation of the self concept of older adults with dementia'.**

Those people named on the 'Keyworker Questionnaires' enclosed have been identified as potential participants. Before contacting them or their carers I must ensure that certain inclusion criteria for this research are met. Please could you assist me in this matter, by completing the 'Keyworker Questionnaires' enclosed. On the return of these questionnaires, I will discuss those people who meet the inclusion criteria with Dr (Name) before inviting them to participate in the research.

Please could you return the questionnaires to (secretary), in the envelope provided by (Date). I will be available on this date to discuss the research and potential participants, however, if you wish to contact me in the meantime you may do so on (number).

Thank you for your assistance in this matter.

Yours sincerely,

Psychologist in Clinical Training

Enc,  
Keyworker Questionnaire

Keyworker Questionnaire

Please could you confirm that the person named below meets the inclusion criteria as specified for participation in this research.

I confirm that:

Name: .....

Address .....

.....

.....

.....

(\*delete as applicable).

- a. Has the person named above received a diagnosis of dementia? YES/NO\*
- b. Has this person been told by the service that they have 'Memory problems' or Dementia? YES/NO\*
- c. Would s/he be able to provide informed consent to participate in the research? YES/NO\*
- d. Would s/he be able to participate in a semi-structured interview? YES/NO\*

If you have answered 'NO' to any of the questions above (a - d) you will not need to complete any further questions, as the person does not meet the inclusion criteria. Thank you for your assistance in this matter. Please return the questionnaire in the envelope provided.

If you have answered 'YES' to all of the questions above, please could you continue by completing the following questions:



1. I have/have not\* seen the person named above within the last three months.

2. The most recent mental state examination was conducted on .....

In your opinion has their been a significant deterioration in the person's condition since this examination? YES/NO\*

If 'Yes', please explain further

.....  
.....  
.....

3. As far as I am aware s/he does/does not\* use the term dementia.

If the term dementia is not used, please indicate the term or terms that are used instead.

.....  
.....

4. Would you be prepared to approach the person named above and to give them information about the research, which I will provide you with? YES/NO\*

If you have answered 'YES', please go to question 6.

If you have answered 'NO', please continue with question 5.

5. Is there a carer or family member who should be informed of the research before I contact the person named above? YES / NO\*

If 'No' please could you advise me of the most appropriate method for contacting the person.

.....  
.....  
.....

**If a carer or family member should be contacted, please could you provide their details.**

**Name:** .....

**Address:** .....  
.....  
.....  
.....

**Relationship to participant** .....

**Has this carer/family member been told that the person named above has a diagnosis of dementia?** **YES / NO\***

**6. Have you any reservations or concerns about the person named above being invited to participate in the research?** **YES/NO\***

**If 'Yes', please specify**  
.....  
.....  
.....

**Signed:** .....

**Name:** .....  
**(Block Capitals)**

**Position** .....

**Date:** .....

**Thank you very much for taking the time to complete this questionnaire.**

**Summary Sheet for Keyworkers**

**Thank you for agreeing to provide information about my research to potential participants.**

**As you have already established a professional relationship with the participants, it will be important that they understand the following points:**

- 1. The research is not related to the care that they receive.**
- 2. Their participation in the research is voluntary.**
- 3. If they choose not to participate in the research, this will not effect the services they receive now or in the future.**
- 4. They are free to withdraw from the research at any time without having to give a reason for doing so. Withdrawal from the research will not effect the services they receive now or in the future.**

**To insure that participants understand that the research is independent from their care, it will be important that you do not promote the research or actively encourage people to participate. Whilst it is likely that people will find it interesting to participate in this research, it will be important to insure that they do not feel obliged to participate, but that they are free to make an informed choice.**

**Thank you for your assistance in this matter.**

**Psychologist in Clinical Training.**

*(Name and Address of participant)*

*(Date)*

Dear *(Participant's name)*

I would like to invite you to help me with a study to investigate the experiences of people with memory problems. I have enclosed an information sheet describing this research. Please could you read this information sheet. Then, if you would like to take part in the study, please complete and return the 'Participant Consent Form 1' in the stamped addressed envelope provided by *(Date)*.

Thank you for your time and assistance in this matter.

Yours sincerely,

Psychologist in Clinical Training with

Clinical Psychologist

Enc., Information Sheet  
Participant Consent Form 1

*(Participant's Name & Address)*

(Date)

Dear *(Participants Name)*,

I would like to invite you to participate in a study. I am a Psychologist in Clinical Training in the final year of my clinical doctorate. I am conducting research at the *(Name of institution)*. Your name has been provided from a research register of clients from the *(Name of Institutions)*. The purpose of the study is to investigate the experiences of people with memory problems. I have enclosed an information sheet describing this research. Please could you read this information sheet carefully. I will contact you within the next week to invite you to participate in the research and to answer any questions you may have.

Thank you for your time and assistance in this matter.

Yours sincerely,

Psychologist in Clinical Training

Enc., Information Sheet

*(Name and Address of carer)*

22<sup>nd</sup> April 2000

Dear *(Carers Name)*,

Please find enclosed a copy of my letter inviting *(Participants name)* to participate in a research project, which aims to investigate the experiences of people with memory problems. I have also enclosed the Information Sheet, which describes the research project. If you or *(participants Name)* would like to discuss this research in more detail, please do not hesitate to contact me on *(Researcher's Number)*

Yours sincerely,

Psychologist in Clinical Training.

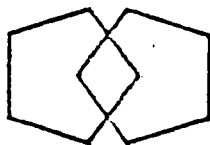
# Mini Mental State Examination (adapted from Folstein et al.)<sup>1</sup>

Patient name \_\_\_\_\_

Date of birth \_\_\_\_\_

Date of test \_\_\_\_\_

Section	Questions:	Max. points	Patient score
1 Orientation	a) Can you tell me today's (date)/(month)/(year)? Which (day of the week) is it today? Can you also tell me which (season) it is? b) What city/town are we in? What is the (county)/(country)? What (building) are we in and on what (floor)?	5    5	
2 Registration	I should like to test your memory. (name 3 common objects: e.g. "ball, car, man") Can you repeat the words I said? (score 1 point for each word) (repeat up to 6 trials until all three are remembered) (record number of trials needed here:       )	3	
3 Attention & Calculation	a) From 100 keep subtracting 7 and give each answer: ... stop after 5 answers. (93__86__79__72__65__). <i>Alternatively</i> b) Spell the word 'WORLD' backwards. (D__L__R__O__W).	5	
4 Recall	What were the three words I asked you to say earlier? (Skip this test if all three objects were not remembered during registration test)	3	
5 Language			
Naming	Name these objects (show a watch) (show a pencil)	2	
Repeating	Repeat the following: "no ifs, ands or buts"	1	
6 Reading	(show card or write "CLOSE YOUR EYES") - see over		
	Read this sentence and do what it says.	1	
Writing	Now can you write a short sentence for me? - see over	1	
7 Three stage command	(Present paper) Take this paper in your left (or right) hand, fold it in half, and put it on the floor.	3	
8 Construction	Will you copy this drawing please? - see over	1	



Total Score

30

Examiner \_\_\_\_\_

Notes

**G.D.S. - 15****Participant Number:**

Please answer 'yes' or 'no' to each of the following questions - whichever describes you best at the moment.

Please circle  
Yes/No

- |  |        |
|--|--------|
| 1. Are you basically satisfied with your life?                         | Yes/No |
| 2. Have you dropped many of your activities and interests?             | Yes/No |
| 3. Do you feel that your life is empty?                                | Yes/No |
| 4. Do you often get bored?   | Yes/No |
| 5. Are you in good spirits most of the time?                           | Yes/No |
| 6. Are you afraid that something bad is going to happen to you?        | Yes/No |
| 7. Do you feel happy most of the time?                                 | Yes/No |
| 8. Do you often feel helpless?   | Yes/No |
| 9. Do you prefer to stay at home rather than go out and do new things? | Yes/No |
| 10. Do you feel that you have more problems with memory than most?     | Yes/No |
| 11. Do you think it is wonderful to be alive now?                      | Yes/No |
| 12. Do you feel pretty worthless the way you are now?                  | Yes/No |
| 13. Do you feel full of energy?  | Yes/No |
| 14. Do you feel that your situation is hopeless?                       | Yes/No |
| 15. Do you think that most people are better off than you are?         | Yes/No |

Score:        /15



Semi-Structured Interview - Section A: Orientation and Awareness of Dementia

Can you tell me why you

1. attend the (*Name of Hospital/Day Hospital*)?
2. see the doctor at (*Name of Hospital*)?
3. see (*Name of CPN etc*)?

Response: If Dementia, Memory Problems, Forgetfulness. Note Terminology: \_\_\_\_\_

Response:  
If unable to explain or remember why.

You have agreed to participate in study investigating the experiences of people with dementia/ memory problems.

Is this what the doctor told you? / Did the doctor tell you, you have (M.P/D)

Response: 'YES'

Response: 'NO'

What did the Doctor tell you? Note Terminology \_\_\_\_\_

If discrepancy: You mentioned X, and said that your doctor told you that you have Y. Where has the term X come from? \_\_\_\_\_

What term do you prefer to use?

What problems have you noticed?

Response: e.g., 'Memory problems'

Response: 'None'

Is it just your memory/forgetting things or have you noticed other problems?

Response: 'Other problems' or examples given

What are these other problems?  
Can you tell me more about these other problems?

Can you tell me more about your memory problems/forgetfulness? Examples.

Response: 'None'

Prompts: Difficulties that some people experience in later life. Do you:

Forget things that have happened recently? Have difficulty finding the right word?  
Forget the names of people that you know? Ask the same things or tell people things more than once?

Feel confused about what time of day it is? Feel confused about where you are?  
Have difficulty planning or organising e.g., dealing with money /or e.g., paying a bill.  
Worry about meeting new people? Worry about going to new places?

Explore/Expand upon difficulties identified:

Can you tell me more about X? What do you find difficult about X?  
What is it that you worry about? Can you give me an example of when that last happened?

**Identifying key relationships and their qualities**

**Who are the significant/key people in your life?**

**Response: Note people mentioned:-**

1. \_\_\_\_\_

3. \_\_\_\_\_

2. \_\_\_\_\_

4. \_\_\_\_\_

**How would you describe your relationship with X?**

**Can you tell me how X is significant/important in your life? Why is that significant/important to you?**

**Prompts.**

**How do you organise your time with X.**

**Who does what?**

**What things do you and X do together? Separately?**

1. **What hobbies/ interests /past times do you and X share?**

2. **Household/Domestic activities - Paying the bills, gardening, cooking.**

**Are there things you used to do together with X that you do not do now?**

**How do you find that you get on with X?**

- **Communicating together (talking/listening)**
- **Decision making/planning**
- **Physical relationship/closeness (If appropriate)**
- **Emotional aspects (laugh/argue etc)**

**Exploring descriptions.**

**Can you tell me more about that?**

**Has it always been like that?**

**What is good/difficult about that?**

**Examples**

**Can you give me an example of when that last happened?**

**Can you tell me what happened then?**

**What did X do?**

**What did you do?**

**How did it end?**

**Is there anyone else who also does that?**

**MOVE TO PART C**

**Is there anyone else who is significant in your life that we haven't mentioned?**

**Prompt:**

**Family Members**

**People you speak with on the phone/write to?**

**People in your neighbourhood**

**People at the day centre/club/church etc.**

## Section C: The effect of these changes on self worth/self esteem

What is that like for you? (*Even if things have remained the same*)  
What is that like for you when that happens?  
What is that like for you when X does .....?

How does that make you feel?

What is it (about that situation) that makes you feel that way?

Is there anyone else that also makes you feel like that?



**INSURE THERE IS A CLEAR ENDING TO EACH TOPIC.**  
**E.G., THANK YOU FOR TELLING ME ABOUT YOUR RELATIONSHIP WITH X.**

**ORIENTATE THE PERSON TO THE NEW TOPIC BEFORE REPEATING THE QUESTIONS.**

**E.G., WE ARE NOW GOING TO TALK ABOUT THE SECOND PERSON 'Y' THAT YOU MENTIONED. I AM GOING TO ASK YOU SOME QUESTIONS ABOUT YOUR RELATIONSHIP WITH 'Y'.**

Participant 6 (ROSE)Part 1

We spoke a bit last time about when you first noticed that you had memory problems.

That I couldn't remember things very well. 1510

It is something that you don't really realise until somebody says to you, 'ROSE I've just told you that' and you realise that you are repeating yourself and that you are not really making much sense and whoever you are talking to you suddenly see that they are looking at you as if to say 'What the hell are you talking about?'. That's when you begin to think 'Yeah, what's going wrong', cause its almost,....you just lose control in a way and then you forget things completely and that's ten times worse (laughed). Because you really and truly can't remember what people have said before and you find people telling you that you are repeating yourself. 'But ROSE you have just told me that' and I think 'I didn't' and of course I did and that is one of the worst things and that is why I sort of feel that I don't really want to meet people and I don't want to go out and I don't want to make contact with anyone (Tearful). So that's the sort of bottom ....(fought back tears).....but other than that it is fine (laughed). Have some tea (laughed) .. Before I start blubbering again.

Reminded that she can stop the interview at any time without having to give a reason for doing so.

No. I'm OK.

There are a couple of things you mentioned there. First, you mentioned that you notice other people's reactions and that people actually say that you have said something before. You also said that you realised yourself that you were forgetting things. What is it like of you when other people mention that you have already said something?

Its .....I just want to....I'm beginning to realise and I say 'Did I say that before? That's a shame, or something like that. I just want to get away. I just want to get out of the room (tearful). Stop it ROSE, drink. But, how can I put it. It is why people who have got this disease must cut off - even more. Because people say come over and see me and I just say 'No'. I mean the lass over the back here she used to come round quite a lot, but I never see her and I know its because I must ~~embrace~~ her. She used to bring the children over but we never see her. Which I find.... I think 'Oh god, she's suss out that I am (pause) stupid and that I can't cope'. Which is fine, cause its not fine to the little children, lets face it. Its not fair to children to keep coming up and asking things and you keep telling them the same things every time. But, um... That's how it is... Anyway, I'm lucky to be here really, lets face it. My worst fear is that ...you know...I won't be able to cope and I will have to go somewhere (tearful- pause). If that happens I'd rather that they found a little pill and shoved it down. Seriously, if that's anybody's (laughed)....You know, if they sought of say 'You shouldn't do that, that's all wrong', its isn't wrong because you are not much use to anyone. And fancy lying in the bed with people waiting on you hand and foot and not being able to talk to anyone other than gibberish. (Got up to get a tissue). ~~There~~ is there a tissue in there love. I've got the sniffles, only a little bit. You don't have to give me the whole role.

1563 Spoke about Zimbabwe. Anyway love carry on. 1564

Are you okay.

Yes, I'm okay now. Thank you. Look at that poor old boy out there, standing there getting his bearing (Pointing to a man standing in the street). I know the feeling well (laughed). There's a lot of old people in [VILLAGE] Its what they call a very desirable place at the moment because it is by the school. He's not likely to go to school, but most people stay here once they get here. Gosh, look there's his wife, bless him. Oh, dear Rose, count your blessings (laughed). See....he's worse.....maybe he is not worse than me. He probably remembers. He remembers to wait for his wife. Anyway love. 1576

You said that if other people mention that you have repeated something you feel like you want to leave the room, but that you have found things that you can say to them.

Yes, but you cut off. I don't know..... I think that you (Pause). Well, cause you don't feel that you belong. You just think I'm stupid let me get out of here. That's it. (Tearful). 1583

So, do you feel that other people think you are stupid?

1584 It was funny we went out the other day. I met a whole crowd of the ladies I used to play. Well girls we used to call them. We're not girls. We're old biddies. Who I used to play golf with. They were very sort of friendly and they did come up and say 'Hello Rose, how are you getting on?' and all the rest of it, but I just found it embarrassing. You do, You just want to cut away. But, if I met anyone with the same problem, I probably wouldn't be feeling like that at all. You'd probably feel sympathetic wouldn't you?. I would think 'Oh my gosh, poor love. What can I do to help'. But if you've got it you don't think like that. You think, 'Oh my god, what an idiot I am. Let them get away'. That's all it is. (Tutted - Tearful). I've got a big enough..... Look what he gave me for a handkerchief (laughed) Gordon Bennett Harry. I don't know what I would do if I lost him. He does everything....well he doesn't..... I do the housework and everything still, but he goes to golf twice a week, which is fair enough. I mean he used to go much more than that, so he has cut back on his golf. So it so of works on the whole family doesn't it really. We went to see my daughter and the children and everything and we left there early because I just said to HARRY, 'Let's go I've had enough' and my daughter rang me up the next day and said 'why did you fly off mum?'. But HARRY wanted to come home because he didn't want to drive home in the dark, but she said ' Why did you want to fly off mum, we had a lovely evening?' and my son who was there as well stayed the night. She said 'We went down to Chichester to the seaside the next day. Why didn't you stay? Cause you could have stayed, we could have managed'. I though, you know. Missed opportunities isn't it. You're running away all the time. You're running away from life really. 1614

What made you want to run away?

I just wanted to come home again. I just feel that I am a pain in the ass to be honest (Laughed). You know... You think 'Oh Dear'. You answer things, but you don't answer then properly and then I see HARRY looking at me, looking ....bloody hell what is she going to say next. But he wanted to leave. I don't know whether he wanted to leave because of me. Quite possibly. But anyway we got home in the sun. It was a lovely evening and a lovely drive. Whereas if you come home in the dark it is as miserable as sin isn't it? We came home the country way which was gorgeous. We came through the back lanes and we didn't see any traffic. It was a lovely evening. And when I got home I was glad that I was home, but then of course when they ring up and say 'what did you go 1626



for?' I missed out again. Really, I think the family are trying to be supportive and the kids don't like to think 'Oh well', you know, 'why have they gone'. But surely when you go they must think 'Oh, Thank god for that'. Well you know. You must speak to tons of people with the same problem (tearful).

Have they said anything to make you feel that way?

Oh, No. No. They are very good. Especially Jules. They are really good. I am lucky. I don't know how people manage if they haven't got a family. God it must be awful. How do people manage? You meet them.

I think it does partly depend on the people they have around them.

Does it? I can't imagine being like this alone. I think I'd go and jump off a cliff. I couldn't cope. So, I say to them, go and get everything you can get (laughed). If anything happened to Haze, that would be that for me. Which is a horrible selfish way isn't it. If anything happened to me at least he would get some freedom wouldn't he? /

Is that what it feels like?

Yes. Even when he goes to golf, I resent it. I do. I shouldn't. And when he comes back he is ten times better. The carer needs as much support as the person who has got the problem really. Because there must be people around who do not belong to clubs and perhaps husbands or wives who haven't got anyone around them and they need support. So your job is pretty hard isn't it (laughed). You have got to support the stupid ones as well as well as the healthy ones from the sound of it. But they do need a lot of support I think.

I wondered what it is that you resent when Haze goes to Golf?

Because he is there a long while (laughed). It is the length of time that he is away. If he only went for a couple of hours, I think that seems like ages. I busy myself. I can still obviously clean the house and everything. I keep trying to get busy and then I try and read a book, but sometimes it seems ages and ages. Which is bad. Its me. I should get out and make my own life. I know what I should do, but I don't. I just can't make the effort, I think people....I just can't. It's like a brick wall. Oh, No. You are safe in your own home aren't you really, basically. That's what it is isn't it. Its what you know.

What is your worry about going out and trying to socialise with people?

Well (pause). The other evening we went to a show, a concert. We went to...it was one of Haze's colleagues down at the [Theatre] So therefore I met a lot of my old friends and they were all very nice and very supportive and I really had a lovely evening. It was nice, really really good. But again I was surrounded by people who knew me and that is like building yourself a little barricade isn't it? Really you know, but they were friendly and they did come up in the interval to speak to us. It was a very good show.

It was a shame though because one of the chaps who is in it, one of Haze's golfing partners, nice chap, chap....he is a nice old boy. Lets face it he is as old as I am. He left early on his own and came out of the theatre and was attacked by a load of youths who tried to grab his bag.....(Continued to recite the story).

Anyway, what else can I tell you that is really interesting?

You were saying that when you went to the theatre you had people around you that knew you and that made things easier. What difference does that make?

I suppose in a way, when I saw where we were sitting and we were right in the middle of this crowd of people I knew. I thought, gosh I wish we were down the front somewhere,

where<sup>1681</sup> nobody knew us, I'll be honest. But in the interval they all come up and were very friendly. You know you go and everybody sits and chats and HARRY is a very good<sup>1682</sup> communicator. I don't know how any couple get on if one of them doesn't.....See he makes friends really well and he is ever so popular down the club and they all shout out 'Hi Jim' and have a joke and a laugh with him. And that is sort of like a bridge isn't it. This is what I was saying, if you have got anyone completely alone with this complaint, I don't know how they cope. - 1683

Do you mean that HARRY is a bridge for you?

Oh, Yes. Yes. Wherever we go HARRY talks to people. If we go into a restaurant and we didn't know anybody he'd be talking to people on the next table. He has always been like that. He's always been ever so friendly. It is like a bridge which could mean that I don't have to bother. I just sit back. See everyone talks to HARRY and I am just nodding and that, so I have never known what it is to be on my own. The only time that we have fallen out is when I went on holiday with my daughter and left him here alone and for about six months it was frosty when I got back you know. He really really resented the fact that I had gone on my own with Julie. But I had a lovely holiday. He doesn't like holidays. See all of us have our little secure units don't we? He cannot bare to go on holiday. He can't bare to leave these shores and he can't bare to experiment or go anywhere other than the golf club. So we all have our own little ways of coping don't we. And even now while I am like this and must be a pain in the butt he never, other than the golf course, he will never go off anywhere. He will never go out. He wouldn't dream of wanting to go on holiday and if I suggested going abroad he would say 'No Way' and 'I don't want to do that'. He likes, well he just likes golf and he likes the old boys up there and they are a nice crowd. They are very friendly and very supportive to him because they know that he is not having an easy time of it. Bless him.

1711 Talking of something else, isn't my bush lovely. You must admire it because it only lasts a week. About a week. It's a lovely colour isn't it. I've had it for about twenty years, but it doesn't last long enough to admire it. Next time you come that will be all gone and it will be just another bush again. Anyway pet this is not helping you. Is that still on (pointing to the tape recorder). When you get back do you read it back and think what a lot of (laughed)..... and that snip little bits out. I used to know somebody who.....what do you call it.....when you....tailor it....no that's not it.....when you pick the bits that are relevant and scrap all the rest. Cause you do don't you, scrap, scrap, scrap, scrap. See what I mean, anyway.

You were talking about that bridge that your husband provides.

Yes

Has that always been the case. Has he always provided that bridge for you?

Oh, he always has. I think so. Yes, he always has. Yes. Although, I don't know. I was a Social Worker and I have worked with a lot of different people, but then again I worked mostly with little ones. I was in this children's home in [TOWN]. It got burnt out. Yes, I told you all this. [NAME] I worked there for a long while. I was trying to think of what I did after that. I must have had another little job. I couldn't have retired and then 1721 packed up work completely. I must have done something else, but I can't remember what it was. HARRY would remember. Did I go to work? I wasn't that old, well I must have been about sixty when I packed it up. OH, no. I can't remember. (thoughtful)

There are a couple of things I would like to ask more about.

<sup>1722</sup>  
Yes, I'm back to normal now (Laughed)

You mentioned that when you talk to people and see their reactions you feel that you don't belong. I was wondering if you can explain what that is like?

It is just....I don't know...just a complete lack of confidence. Your not sure that anything you say is going to be really of any interest to anyone. I think that...I don't know...I do tend. Wherever we go I do tend to sit back and listen now because I don't have the confidence to join in with the conversation, which is crazy really, but I just wonder what.....You know I might say something stupid or they will look at me and say 'What are you talking about' (Laughed), which is true it happened I am sure. I'm sure. Have you got many people around like me on your books. Says me being very personal.

Yes.

<sup>1733</sup>  
It is something that goes with old age then. Or is it hereditary? You don't know.

There are believed to be various causes. I don't think there is one answer to that. Certainly, I work with a lot of people with memory difficulties. And because this is an area of interest for me with respect to the research I am meeting a lot of people with memory difficulties.

But it is mainly the elderly. It is as you get old.

Yes that is the case, although there are some people who are younger who experience memory problems.

I wonder if.....I wonder what brought it on. I think a lot of it is in the genes isn't it. It is definitely, must be a genetic thing. It must be. Its funny because Dr. Smith said to me 'Oh, it's the genes you see' and when I mentioned it to the other young lady, she said 'I didn't know that, he doesn't tell us anything. He never says anything'. And I thought at least then you know that they are not sort of.....I used to think that once you have been for a visit they all sit down and discuss, but they don't do they really. They are very good up there. She said 'Oh no, he never discusses you case with anyone.' Which, he has every right to do so as that is his job, if he wants to, but it is comforting to know that....well....what harm does it do. It doesn't do me any harm if they talk about anything does it really. People don't know you do they. It doesn't make any difference if they do I suppose.

What would be your worries if they were discussing your case?

Yeah, I had never really thought about it. It doesn't really make much difference does it. It is just helping other people in a way. If it is going to lead to other people understanding what might happen to them or even helping the people like me. Its all got to be discussed. If we swept it under the table and pretended that it wasn't happening no body would get anywhere would they. We would all .....it wouldn't be much point in being....well we are all supposed to be caring, is that what I am supposed to say and you always help people who are down. So if you are giving something, if you get people to tell your experiences the people doing the job will know what to look out for in other people when they come along. -

As with this research is in an attempt to find out what people's experiences are.

Yes, because you don't know. You don't understand.

Unless we ask people like yourself.

You'll never know, that is true.

Is it mostly in the elderly. You don't get this in younger people do you?

Occasionally. A majority is in the elderly.



I wonder if it is in the genes though. I said to X who visits me, I know I said to her Dr Smith said it is in the genes. She said Oh, I've learnt something today, he never tells us anything about anybody's cases. And I thought Oh dear perhaps I've spoken out of turn. But it doesn't really matter does it. I came from a big family and two of my brothers had horrible endings, which, we always said it was in the genes and so I wonder if it is a family thing. You know. That something is wrong in people's genes. But there you go. It is something you can't control isn't it.

I suppose I was wondering what difference that makes to you knowing whether or not it is in the genes.

I accept that because I can remember when I was a little....because I told you I came from a big family, when I was a little tiny girl I can remember my brothers who were a lot older than me, I can remember when they died. And to me I think well it is in the genes and that sort of...to me makes it a bit easier because I think well what will be will be. It was something that has been born. I just hope that as life goes on it goes less and less and less because I would hate to think that any of the kids would face this in later life. You know, my children.

So it is a worry for the future?

Yes. Yes. It's just good to know that people are trying to find out and help. Because it was a lot worse years ago. I can remember my brothers...they weren't young people but they had a rough time at the end of it and we always said its cause we could never understand that I had ....I told you I had three older brothers, STAN, CHARLIE and DON. Lauri was the oldest one and he was the one who went doo-lally, there is no other word for it. And he was the womaniser and the drinker and lived life to the full as you might say. While DON was a different type altogether. He was a gentleman and a real sweetie, but he got it as well. He had this awful time at the end and so today I think if I was living....if it was the same time, like if I was the same age as them I could be in the depths now, couldn't I? I mean...I haven't got any complaints. I've got the garden. I've got the house and I've got HARRY and I've got the kids coming in. But Ken and Lauri were just whisked off. It is so different. It was the same with HARRY'S father, not that HARRY'S father is anything to do with me, but he went funny and although he was a nosy old bugger and the rest of it, as I told you. He was a smart little man and he was always nicely dressed and liked to fancy himself. Well we went to this home with him (pause) and said goodbye and the next time we saw him..... Oh god... he was dressed in..... Oh trousers tied round him and oh it was dreadful and his wife said to him where are your clothes and he said 'took them away'. And honestly, I mean I hope things have got better, but it was ...it was absolutely ghastly, awful. Poor old boy (laughed).

I was wondering what that was like for you talking about it being hereditary and in the genes and wondering how that leaves you feeling.

Yes, you do. You wonder and you just think, well there has been a great advance hasn't there. Like talking about HARRY'S dad who had such a dreadful time in that home and how people get treated now. Touch wood, I haven't been in a home. I mean dad. I told you didn't I that he took all the beds to bits. Stacked them all up against the wall. The whole ward. He dismantled the whole ward and yet he was in a place where he was being watched and nobody even missed him and he was in there for hours apparently. He took everything to bits. It is no wonder he didn't take the curtains off the wall. Everything was ever so neatly done, stacked up in the corners. Poor dad. But that was HARRY'S dad.

Nothing to do with my genes (laughed). But other than that we have had a very easy sort of life. I was just trying to think. I can't remember when this all started. You see, it is not all doom and gloom because I am the lucky one, I know that are an awful lot of people a lot worse than me and I have got the garden, I've got the house and I've got HARRY coming in every so often. Well he's with me all the time. He is always there. I often think what would happen if anything happened to HARRY. What would happen, which is a completely selfish outlook isn't it?

And what is your worry about what would happen?

I would be dumped into a home and that would be it wouldn't it. Because I couldn't expect the children to take me on and that is just what happens. I just hope that I go first, which sounds a bit hard on HARRY but perhaps that will leave him to have a little bit of time to himself to enjoy life. Wouldn't it really. And let's face it I am seventy and I have had a jolly good innings or am I seventy two (laughed) I can't remember. Anyway, I have had a jolly good innings haven't I? Because we were a big family and they were all gone by the time they were sixty-six sixty-seven. I think ROSE you have been jolly lucky. And funny enough my twin sister is fit and healthy and everything and doing well. She phones up occasionally. But, I am very lucky. Really lucky. I just wish I could remember things (sigh)

I wonder if I could ask a bit about the problems you have noticed. You spoke about forgetting things when you are talking to other people and how they point that out. But also you mentioned that sometimes you notice that as well. Other than memory what other problems have you noticed.

None really. The only other thing is if I go for a walk I sometimes worry in case I won't remember the way back and I often feel very lost I suppose but I am not lost and I get back. But I do feel... and I couldn't imagine going for a walk on my own and I wouldn't want to do that. We do go for walks obviously.

What is that feeling like?

Well it is just as if you don't belong. I can't describe it (pause). It is..... you are not quite sure which is the next turning and I don't think if I was wondering around I would have the nerve to go and ask anybody. I would just sit in the corner and hope that I get better, but it's horrible (tearful). That's why... I don't know. People do cope on their own don't they. I mean, lots of women live on their own. I was trying to think of somebody I knew. Oh yeah, I do. There is a woman I used to be friendly with, from years and years ago. We must go and see her. When I was younger I used to drive her around a lot because she didn't like driving. She was a counsellor and she has just moved into the village and she's on her own a lot. Now, really I should nip down and see her and say 'Hey' I can't even think of her name. You know 'how are you doing' and do all the things you do, but I can't and I keep putting it off and off and off and thinking Yes I must go and see her but I never do. I haven't got the nerve to go and knock on that door and so my confidence has gone and I'm sure that she would be quite pleased to see me.

I know you said confidence but what do you think puts you off.

Yes, I should just go down and knock on that door. Now that's confidence isn't it. But I haven't got that confidence and if I went I would have to have HARRY with me. I wouldn't dare go down there on my own even though HARRY has told me where it is she lives and has given me the number and said she is down there on her own and she'd be pleased to see you but I haven't got that confidence.

What do you think worries you about doing that?

I don't know whether it is rejection or whether its... I have never really analysed it and I've never really thought now why don't I do it. I can't imagine going and knocking on that door and it's a thing you would do normally wouldn't you. You would say 'Oh a friend has moved in, I'll go and see her'. But I can't go down there. I think its because I think I haven't got the confidence in myself. I will probably start saying stupid things and she would think 'Oh blimey, what has happened to her? And rejection again isn't it. It comes down to rejection and when she'd realised there was something wrong with me, it would be rejection wouldn't it? You know, you would think 'Oh gosh, I am not going to waste my time on her'. So that's basically it, it's a fear, a fear of rejection.

How does that make you feel?

It's selfish I suppose. It just makes me feel well I just won't bother. It is selfish because there must be people out there who are lonely like me but I just haven't got the confidence to go out and make contact anymore.. It's sad really. Gosh I used to drive ~~CLARE~~ around all over the place because she didn't like driving and so she would say 'Come on ROSE I want to go here there and everywhere' and I used to think 'What the hell am I doing', but there again he was on the golf course. But ~~CLARE~~ is older than me I think. But she has been a very busy busy lady you know. She must feel terribly lonely and yet I haven't got the confidence to go down there. I must be honest, in a way, if I go and see ~~CLARE~~ that means I'm going to start becoming responsible for ~~CLARE~~ If you think honestly, I'm beginning to think... I would think now I must go and see ~~CLARE~~ and honestly its just pure selfishness because I don't want to take on... how can I explain it?... ~~CLARE~~ is a very dominant lady and before I knew where I was I would be running round in circles trying to keep up with ~~CLARE~~ I know how it would be and I would be doing her shopping and I would be doing everything and I think 'No I can't do that'. So instead of taking the bull by the horns and going down there and seeing her I haven't got the confidence to do that or maybe I am plain lazy or perhaps I am just being selfish. I mean I think I know ~~CLARE~~ 'I don't think I could take you'. Because I used to run around a lot for her. I used to drive her everywhere, to all her meetings. Well I can't drive, so maybe I wouldn't be much use to ~~CLARE~~ (laughed). Well I can drive but I wouldn't dream of driving. It wouldn't be fair to other people on the road. Well ~~HARRY~~ won't let me drive. Who was it who we met once who had very much the same as me and she was driving? And I said 'But ~~HARRY~~ she is driving' and he said 'Yes, but that doesn't mean you are going to. Which is fair isn't it because you only hit somebody once don't you? But she was still driving and she had got my problem. I don't know how she coped but she was driving. Or perhaps I just dreamt that. She wouldn't be driving if she had got Alzheimer's, never, would she?

Usually not.

No. No. She couldn't be. I must have dreamt that. She couldn't be on the road driving. I'm going to find out when you have gone (laughed).

Sometimes people experience difficulties in different areas of day to day living. Can I ask you about some of them?

Yes.

I'm not expecting you to have experienced all of these. it is just whether or not you do.

OK love.

Do you ever find that you forget things that have happened recently?

1909

Yes. Yes. I do forget things that have happened recently.

Do you remember the last time that happened to you?

That's a difficult one because....things that have happened to me recently. We went over to Julie's and I can remember that as plain as anything. I remember driving home and everything yesterday. I can remember the children being there and everything. (Long pause). No I can't answer that one.

What's it like for you when you realise that you had forgotten something?

I feel a bit panicky. I feel useless and what an idiot basically. It's a bit scary too because you wonder where is this heading. As I say, if anybody hasn't got any support I don't know how they cope at all. I don't think you could cope...well you couldn't cope on your own and I'm not saying nursing and people who help in these places are not supportive but its not like a partner is it. I mean ~~Harry~~ is absolutely marvellous and must get fed up to the teeth. He doesn't say it, but he must get fed up to the teeth.

I was wondering what impact that has on you thinking that he may get fed up?

Well, I just feel.....sometimes I think it might be a good idea if I went away and gave him a break. If I went and stayed with my daughter.

Do you find that you forget the names of people that you know?

Oh yes. Yes I do. Definitely. ~~Paul~~ my son, he's just met this girl and yesterday I just sat there in this room talking and thinking please someone call her by her name, because I can remember your name and I know that I do know it. And I kept thinking all the while and then suddenly it came to me before somebody said it. I said 'Sue' and she said 'Yes Rose' and I thought 'Thank god for that I've got it right' (laughed).

So, it came back to you.

Yes, it came back in the end. But, I couldn't remember it and I had met her before and she had been here, but I thought whatever is that women's name. And she doesn't look like a Sue, if you know what I mean. She's very down to earth sort of person. Did I tell you that Ann rang up to say that they were sorry that we had left early and that they had a wonderful time and that Paul, this lass and his boys stayed the night and they all went down to the seaside the next day and why hadn't I stayed, you know. And I thought 'Ann I couldn't have done that anyway'. We couldn't have stayed. I mean, she only lives in a little time house, where would we have slept for a start? She would have given up her bed I know. But, you know. It just wasn't possible. So she said 'Why did you go home mum?' But Harry wanted to escape as well as me. So maybe its something in him as well because he said 'Oh dear, I want to get home Rose'. So maybe he is beginning to want his space as well. I don't know.

What made you want to escape in particular?

We had just had enough (laughed). I felt too that it was nicer for the young people to be on their own. Which is a lot of...you think.....let's get out of this. Ann obviously said the next day 'Why ever didn't you stay?'. But really it is a feeling that it is time to escape. Perhaps your mum even feels that way if she's with all the family. She thinks 'let the rest of them have time on their own'. Which is just normal isn't it. I mean that's what all families do, I should imagine. I mean cause lets face it. Its all to do with age again, but you know when you are getting older you want the youngsters to have a good time. You don't want to be sitting round...you know. It was a real family gathering. It was wonderful and I thoroughly enjoyed it but after a while I just wanted to get home. But

surely that is just old age and I don't know how that can be mixed up with Alzheimer's. That's part of life isn't it.

When you find that you forget people's name what is that like?

Horrible. Awful. You just hope that somebody is going to mention their name or it is going to come to you. It does come after a while. With this girl Sue, for a while I just kept thinking 'Oh somebody say what her name is because I don't know what your name is'. And suddenly I was talking to her and just I said 'What do you think, Sue?'. And it just came out and I thought god that was the right one and nobody.... And I breathed a sigh of relief (laughed). I say girl, but she is older than you.

When you say 'Horrible' how does that make you feel?

Horrible?. Well ...useless. Horrible and not coping and wanting to run away and wishing there was a corner you could disappear into. As soon as Harry says 'lets go' I may be having a wonderful time, but I want to go. You know. And I can see the kids.....Julie, she's the most caring one of the three. She rings up and says 'Why didn't you stay mum? You missed out on a good time'. But to me I felt that I had to get away. I feel that, how can I put it...You are a pain in the butt. You know (pause & tearful) and its selfish because the kids are all running around everywhere and I thought 'Oh gosh, you know, lets go home'. But it was Harry who amazed me because he said 'come on, lets go home' and I don't know if he saw that I was getting stressed out or if he really did want to go home. I will ask him (laughed).

What affect does that have on you to feel that you are a pain in the butt?

Well it is a pain in the butt. It is a pain. Anyone with this will tell you that you are a pain in the butt. You don't know whether you are coming or going (tearful). You don't know ....Your just a nuisance ....really. I mean.....(Sigh). Just pray you don't get it yourself girl, which I am sure you won't. They would have found the answer then wouldn't they? Oh well, I don't know. I don't know. Anyway, as I say. I have got a wonderful life really. I've got a happy home and I am still in I, a nice garden, cars buzzing past every five minutes so you don't feel you are alone in the world (laughed). Cause there is a lot said for being quiet in the country but it must be a bit lonely, whereas there are people always walking past. I am very lucky.

Do you ever find that you feel confused about what time of day it is?

Oh, yes. That happens.

Can you remember when that last happened to you?

Well sometimes if I am alone here I sometimes think 'Oh dear, Is it anywhere near dinnertime. Is it now the time that I am supposed to be eating or something.' Which.....how can I put it. Which doesn't mean to say that I would want to go into a home and have people bring my food in on a tray. I am quite able to go and cope and put my own meals on and I am quite able to fry eggs and bacon and do all the cooking, cause I do it. But I have a feeling that if I was here alone I would forget about food. Or I would go out there and have a slice of bread and jam and that would be my dinner. I wouldn't bother if I was here alone to cook. No. I couldn't be bothered to put a joint in the oven, or have a roast and all the rest of it. Which is bad isn't it because I am getting a bit like that now and its not good for Harry. He should have his meat, veg and the rest of it.

And are you the one who does all the cooking?

Yes, I still cook.

What is that like feeling confused about the time of day?

1993  
It's a bit weird. It's a bit scary. I just come in and look at the clock and realise oh well its  
1994  
okay. Right now, it's twelve o'clock. It's okay, I'm okay. But I can honestly, if ~~they~~ went  
1995  
off for the day I could stay in the garden all day. I don't think I would come in at all. I'm  
1996  
not worried about food. You know. I wouldn't.....I suppose I would come in and do  
1997  
myself a bit of toast or something. I would never cook for myself. A lot of people don't  
1998  
anyway do they. There are so many convenience food about.

Do you ever find that you have difficulty planning and organising things?

2001 I have to write things down and I often wake up and can't remember what day it is which  
2002  
I think must happen to a lot of people like this. I also.....I have a cleaner as you know  
2003  
once a week. But she hasn't been this week and I haven't missed her. I have quite enjoyed  
2004  
the fact.... and in a way I think 'What am I paying her eleven pound a morning for? Its  
2005  
not worth it, I'd rather do it myself. But you see ~~they~~ won't let me do that because he  
2006  
maintains that I wouldn't do it properly. Which I think I do it fine, but he says 'No,  
2007  
Wendy gives it a good clean' and I don't apparently.

So, you mentioned that you write things down when planning and organising?

Yes, I try. It is no use trying to remember. So if anything is.....I should say now that I  
2014  
have an organiser shouldn't I but I haven't (laughed)

Have you always been the kind of person who writes things down?

No, never. Never 2017

So, that is a new thing.

Oh no, that's a new thing. That is something that I am trying to..... just 2018  
myself, so that it is something to give me something that I can look at and think 'Oh yes,  
2019  
that is what I am going to do'. But if I do that and then I go in the garden, it doesn't matter  
2020  
what I write on that bit of paper cause I would stay out there and I mean it is only a little  
garden. But yesterday, it is a little garden as you can see, but we have a garage there and  
2021  
yesterday I was digging out there and I happened to go behind the garage. Well it is an  
absolute tip and that is only round that corner. So I spent the next two hours clearing out  
2022  
brambles, cutting back stuff that you had no idea...and I thought why hadn't that girl at  
the back there come and said to me 'Joan, your place has overgrown?' Honestly, it was  
2023  
disgusting. There were brambles miles out hanging.... Huge great things and I thought  
2024  
'Oh my god', I am a keen gardener, I go out there everyday, and I hadn't seen that. So  
2025  
there is something wrong somewhere isn't there. I mean it is only at the back of the  
garage .....and where the garage is there is a little space. Why that was left I don't  
2026  
know. I suppose it was to do with the building regulations. So that is just full of weeds,  
but I just turned a blind eye to that, but I have never seen....and I always kid myself that I  
2027  
only have a little garden and that I can keep it tidy but it was a tip out there. Now that  
2028  
shouldn't have happened, but things like that I can forget. Other than that I don't really  
2029  
plan my day, I just get on and do things.

Do you ever find that you have difficulty finding the right word?

Yes. Yes I do. I try and think now before I even start burbling. I am just afraid that I will  
2030  
come out with something stupid. So, I try....and if we are in a crowd I try and keep quiet  
(laughed), so I don't say the wrong thing. Which must be another part of Alzheimer's.

So, you try not to be so involved in a way, as you were describing earlier.

Yes, so I can stay out of the conversations and keep quiet. Then you know that you are  
2031  
not going to make a fool of yourself. I was just going to say if they is why ~~they~~ suddenly  
2032  
said 'Come on, lets go home' so early yesterday, on Saturday, whenever it was, when we

were there with the family. I will ask him if I embarrassed him at some stage, but he wouldn't tell me if I did. If I had embarrassed him. He will never tell me. It would be more helpful if he did because I would try and not do it again. I sometimes feel as if he is rescuing me. Do you know what I mean? Thinking we've got to get her out of here before she says something really stupid.

What would you like him to do?

I wish he would tell me. But, then again that is hard isn't it. Cause if he does tell me I get ever so mad. I ask him what the hell he thinks.....and I turn on him. Its not easy for the husband. Have you got anybody people to come and talk to him.

There are groups and support networks set up for carers.

He should go. He should go. We tried the other one, but we couldn't hack that one at all. But not he should have some support I think. Because he must get fed to the teeth mustn't he. When you marry somebody you don't expect to put up with this at the end of your life. Ooh.

How would you describe your relationship with your husband generally.

We have got a very good relationship. We have. We have got a good relationship. He is very caring. He always has been, other than where golf is concerned (laughed). Lets get our priorities right. If he was told 'look here, what are you going to pack up your wife or your golf?' he'd say 'My wife', I am sure (laughed). He does absolutely love it. It is not just the golf is it, it is all the old boys getting together and it's an escape. And lets face it he deserves it I suppose, but I don't always feel like that I'll tell you. I get a bit sort of .....when he gets home if he is a bit late I get bit uptight. It's not fair because he doesn't have much of a life.

What kinds of things do you two do together. Do you have hobbies and interests that you share?

Watching the telly (Whispered & laughed).

Watching the telly?

You didn't hear me say that did you? (laughed)

Is that not a good thing?

Well, I don't like him to come and help me in the garden, because I don't want him out there and other than that.... we go walks together. Of course, we have the dog and we go for long walks then. But, we don't do much together.

Has that always been the case that you haven't done much together or is that a new thing?

I can't really sort that one. We have always had a good relationship and we have always been there for each other and I don't know.....its....cause ~~Harry~~ did have that bad break down, so he has had sort of a bad spell. Once I went on a holiday with Julie for which he has never forgiven me. He has always been very bitter about that because I left him on his own. I mean I just thought he would play golf all day (laughed). Forgetting that there were meals to be cooked and the house is very lonely to come home to empty house.

It sounds as though things have stayed the same in terms of how much you do together.

Oh yes. We have never....we don't live in each other's pockets as such, but he ....I was trying to think of when he had that breakdown. He had a break down. Maybe that is why he is so much more patient with me. He had a bad time, but I don't think....I can't even

2073  
remember whether he went to be looked after or anything. I don't think he did. It's a long long while ago. Years ago. 2074

I wondered if there are ways in which you feel having memory problems has had an effect, if at all, on your relationship with your husband?

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Not really. Not really. No it hasn't because we are still very close. I know that he cares for me and I care for him. That's just the way it is. That's just life. I couldn't imagine how it could be any different. I suppose we are lucky in a way and we are not youngsters are we. We've have had 2080 a good innings as we keep telling each other every so often (laughter).

You remind each other do you?

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Yes, we do now and we are lucky that we are still in our house. I mean we are not in a bungalow or anything yet, which might be the next step. We love being here, but if you can't climb the stairs.. I mean the old lady next door has got a thing that slides ups and down the stairs and she manages and she lives alone. She is wonderful. But then again she is lonely. She used to come in, but she doesn't now. I think she finds the conversation with me too wearing. I keep repeating myself. So we don't see her now. She used to come round quite a lot.

You mentioned a couple of people from round here who do not visit any more and I asked about your husband but I was wondered if your memory problems have had an impact on other relationships.

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We haven't got the friends now that we used to have. ~~Harry~~ Only contacts now are at the golf club and I really haven't got....I have a cleaner, she's great (laughed). But I mean that's a contact I suppose. Once a week she comes in. Other than that we don't really see anybody much. Other than people calling in to see ~~Harry~~. Like this morning the ol' boy was over because something had gone wrong in the house and they just knock on the door to talk to him about odd jobs. Not that he is an odd job man, but people tend to come and ask him if he can help because he is that sort of person. But, no. I can't remember the question now and that speaks for itself.

In terms of friendships and relationships. What was the situation before.

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We used to socialise quite a bit. We used to have quite a few friends that come round. We used to have people over for holidays and do all the things that people do, but when you get older you don't do those sort of things anyway. You don't. I mean for one thing you get too old to travel and for another thing.....and ~~Harry~~ which I felt was demonstrated on Saturday with the kids, he wanted to get home. And so... and I to be honest, I sat in the car coming home thinking 'Have I done anything, that he wanted to get home quickly?' And I don't like to ask him because he then gets upset and it's a vicious circle.

You mentioned last time I visited that you used to play golf. How is that now?

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2124  
I do miss it. I do miss it a lot, but I have had....I met an old friend who I used to play with and went up to [NAME] Castle and played and I did enjoy it, but I felt that she didn't enjoy it so obviously I didn't play very well. But when I left her and we said 'Cherio' she had obviously noticed that things weren't right with me because she suggested that I take up painting. She was good actually. She said that she found it...not stimulating....very restful. She said if you just get a sheet of paper and get some paints...and I thought 'That is a very good idea', I will do that, but that is three weeks ago and I haven't done a thing about it. You see so, even when people try to help I don't do it. But she....and I thought yes that would be very restful, sitting here, but she said you must do it from still life. You don't just copy it from another picture. You have got to have something that you are



really going to do and that all takes time doesn't it. You've got to think of what you are going to do and then you've got to think where you are going to get the papers and then it goes on. I think I will try and do that. Something instead of sitting here all day watching telly. It's not good for you is it, but a lot of people do it don't they.

What are some of the difficulties that you have found playing golf?

I used to love my golf. Well for one thing I just didn't feel one of the crowd again. I think I got worried about putting my foot in it, then ... they were a nice crowd of women I am sure they were, but they were very chiquey. Perhaps you have never come across a clique of women but I always got the feeling that I wasn't coping and I wasn't doing it well and I thought Gordon Bennett I mustn't do this. And funny enough as I told you, I went up with ANN, but I played quite a good game with ANN. Then this other friend of mine who I used to play with rang me up and said 'Ros', come down and play a game of golf and we went over and I couldn't hit the ball. You see I mean, she's great May and she said 'I'm going on holiday but when I come back we will have another try' but I haven't got the confidence now to even have another try because I couldn't hit that ball and it was as though I had never played golf. And I used to be quite good and I had a handicap and everything. She didn't say anything but I could sense that she was thinking 'Golly, what the hell have I taken on?' which I would have done in the same way and I certainly don't expect to come back.

What was that like for you?

Oh I felt a bit gutted. Well I did feel a bit gutted when I got home. I spoke to her about it afterwards and she suggested that I take up painting, which is very kind of her, but I felt well that says it all doesn't it?

What did you feel it was saying?

You can't play golf so get painting women (laughed).

What impact does that have on you?

Well it didn't make me mad because it is my own fault, but it made me feel that I had lost another skill. Lost another friend and that I was on my own again (tearful). That's good isn't it, it sounds like a song (laughed). But May was only trying to help obviously which it was a nice though I suppose (sighed). Funny old world. Anyway love.

You don't want to hear all of this driven love. Stop. I think I've said all this once before so we will stop. I just hope you find a cure if there is such a thing. Oh dear. I should think you must get bored out of your mind.

No. Not at all.

You do love. Honestly. You must go home and think bloody hell. Would you like another coffee?

No thank you. Does it feel like it has been a long session?

It feels like it has been a long session for you. I think my goodness you must think 'Gordon Bennett'. You've drained the jug dry.

Have I drained you I think is the question?

Oh, no. I haven't been doing anything, just sitting here talking about the past.

### 3.4. Participants reactions to the recognition of their symptoms of dementia

(Corresponds to Table 4)

#### 3.4.1. Immediate reactions to a recent episode of e.g., forgetting.

##### (a) Negative Emotional Reactions

###### Awfulness:

Dorothy (780/1) **Confusion:** Horrible. Horrible....Just knowing that it's going to stay like that.

Rose (1846) **Lost:** Its horrible (1954) Horrible. Awful.

June (179) Oh, it was horrible, really terrible (182) It was horrible, it was awful.

Donald (906) Not remembering anything at all, its terrible.

###### Strangeness:

June (201) It was peculiar, very peculiar

Margaret (449) I have this strange experience and an important fact will become an absolute blank.

###### Sadness:

Rose (1847) **Lost:** Tearful

Margaret (484) It makes one feel very sad

David (2616) But it does upset me a bit especially if I am dying to say something and I can't get it out. But not often.

###### Worry:

Rose (1835) The only thing is if I go for a walk I sometimes worry in case I won't remember the way back and I often feel lost I suppose but I am not lost and I get back. (1915) **Forgetting:** I feel a bit panicky. (1917) it's a bit scary too because you wonder where is this heading. (2036) I am just afraid that I will come out with something stupid.

Charles (1323) I know this area right up to the Elephant and Castle, but I am always frightened of getting lost. (1330) It is very worrying. (1331) that I will get lost.

Margaret (445a) It certainly worries me when I can't get a clear picture or a clear memory of what was said or what was done on any given occasions. (458) **Forgetting:** I get very worried (463/4) Almost anything can cause me to worry. Especially if I have forgotten something. (465) Its just that I worry about not being able to remember. (449) If you are confused it is very worrying because there may be an important date one has been trying to remember for some time and you just get it confused.

Donald (1079) I always worry when I go for a walk round the roads that I don't come back. That I go the wrong way to come back and get lost I suppose.

Annoyance & frustration:

- Charles (1215) Gaps: It's a bit frustrating. (1249) Concentration: I can't cope with it. Its not a question of basically concentration, it is a question of being too long to tolerate.
- Margaret (459) I get worked up and the more worked up I get the less easy it is to remember.
- Donald (960) Confusion: time Frustrating
- Stan (2909) Well, it feels a bit, um, You feel a bit annoyed with yourself. Its annoying. You think to yourself, 'How on earth could I forget that?' But you do.

Guilt:

- Margaret Re: Failing in ones social duties to others.  
(475) Forgetting names: You feel remiss. After all the name of the person represents the person. (485) One feels guilty for not realizing the importance of the other person. (481) Now people are important therefore one feels one has failed in ones duty towards that person if you can't recollect their name.

**(b) Adjusted Emotional Reactions**

- Anne (2729) Forgetting events: But now I am used to it so I don't take any notice of it. (2754) Feelings re forgetting: Not really, I don't think.  
(2870) When I had the stroke I noticed it more, but as times has gone on I have got used to it, so I don't take any notice of it.
- George (2324) Names It doesn't worry me anymore. Finding word (2407) Don't think that it worries me very much.
- June (85) I couldn't care two hoots now.....so I forget, so what. No, it didn't worry me at all.

**(c) Immediate cognitive reactions**

Questioning:

- George (2250) What is the matter with you?
- June (173) Confusion: and I got up and thought this is my place, but how have I got here? (188) I thought, "Why did they bring me here?". This isn't my place and yet it looks like my place. (193) I thought to myself, "Alison will come in", but she didn't. (200) And I thought, how come I came here and this is my home and I've got to go home. (204) It hasn't really gone yet. I still think of it, How? Why? Was I in a place, my home and yet it wasn't my home.
- Stan (2897) I can go from one room to another for an article, but when I get there I think 'Now what have I come for' and I have got to sort that out. (2903) I think 'What have I come for?' (2932) Confusion re: time: I think 'now, where am I? What am I doing?' (3039) I feel "Why can't I think of it?"

Confusion:

- Margaret (441) I get into such terrific muddles cause I can't remember little things. (443) I have a confused picture in my head of something that was said or something that was done. (461) Generally, I am in a terrific muddle.

Ruminations:

- Dorothy (796) .....turning over and over

**(d) Denial - (Age normalising)**

- June (71) I say to people 'I'm old and forgetful now'
- Anne (2732) I know that I am getting old
- Charles (1187) I put it down to growing old

**(e) Avoidance - Social avoidance and withdrawal**

- Dorothy (788) At Christmas time when there were parties I didn't want to go because I thought that I looked so awful.
- Rose (1681) Theatre Visit: When I saw where we were sitting and we were right in the middle of the crowd of people I knew, I thought, "Gosh, I wish we were down the front Somewhere where nobody knew me"..... (2037) If we are in a crowd I try and keep quiet so I don't say the wrong thing...So, I can stay out of the conversations and keep quiet. Then you know that you are not going to make a fool of yourself. (1961) Names: Wanting to run away and wishing there was a corner you could disappear into.
- (1685) He is ever so popular down the club and they all shout out 'Hi Harry', and have a joke and a laugh with him. And that is sort of like a bridge isn't it?... (1689) Wherever we go Harry talks to people...(1691) It is like a bridge which could mean that I don't have to bother. I just sit back.
- David (2624) Right word: It was a conversation, but I made out 'Oh, I must go, I must go' and that was the end of that.

**(f) Avoidance - Minimising the problem**

- David (2566) Names I didn't have any trouble obviously because you don't have to worry if you don't know the names of people. Confusion re: place: (2645) It doesn't really worry me too much.
- June (87) So I forget, so what? (104) No, it doesn't embarrass me at all. (118) It didn't worry me at all. (166) Repeating self: It didn't worry me at all.
- Charles (1186) I don't let it worry me. (1203) I am not a worrier. I don't worry, Worry is a bad habit. (1225) I don't let it worry me and if you don't worry about something it is not so important. (1188) There is no point in getting rattled about it.
- Stan (3079) No I don't worry very much. I am not a worrier.

**(g) Acceptance of the problem**

- Charles (1278) I accept it

### Normalising the Problem:

- June (99) I think some of them forget themselves now. (119) A lot of people there [day centre], they forget the same as me. (145) You've got to have something wrong with them to be in a place like that [day centre]. You see, that's how you know that there is something wrong with each of us.
- George (2343) You can't help it can you. That's the way that I see it.

## 3.4.2. MANAGEMENT STRATEGIES

### (a) Social Interventions

#### Admit problem:

- June (96) I say to people, "Sorry. I am not good at names". (105) Well it helps because you speak up, you say "Look, forgive me but I forget names". (106) If I've forgotten your name I say "Don't take any notice of me". (167) I'd say, "Oh, I'd forgotten. I forget I told you". (168) I would say, "Oh, I'm sorry, I've just remembered I told you before"
- Margaret (436) I have mentioned to quite a few people that I have memory difficulties.
- George (2341) I just make it known to whoever it is, that if he has given me his name or her name and I have forgotten it, I just apologise and sometimes I don't do that. (2355) Now, if they obviously know me a lot of them, if I have to I just tell them, you know outright. I've got this disease and they just look at you funny.
- Stan (2900) But, I am afraid that I am forgetful.

#### Obtaining answers by asking others:

- David (2567) Names: You can always ask can't you. **Confusion re: place** (2643) I usually have to stop and ask someone.....If I am really lost, then I can see someone coming that I know or maybe don't know, but I can still ask the question.
- Margaret (475) I try and ask them. I endeavor to discover peoples names. It depends how important the person concerned is. (473) **Forgetting conversation:** Well usually, ask the person concerned and see if one can find out what actually happened. (455) Well I usually enquire and go on enquiring until the penny drops.
- Donald (951) Well I just have to ask (wife).

#### Prompts from or for others:

- David (2582) But May is terrific, she says 'Well you remember him' and it comes back.
- June (120) Being in a place like you are not on your own to forget... and one of them says 'This is your bus'....and you don't get the chance which is good thing.
- June (94) I just say, I'm June'

#### Accompanied by others:

- Charles (1324) **Getting lost:** (Wife) comes with me.

## **(b) Practical Solutions**

### Use of timepieces:

- Charles (1315) I look at my watch to see what time it is.
- Donald (954/61/2) If I hadn't got a watch I wouldn't know what day it was. It has the day and the date on it. ....I suppose it helps.
- Stan (2928) ...You look at the clock and see the time ..'

### Written Prompts (including Calendars & diaries):

- Rose (2002) I have to write things down (2019) Just mentally remain myself, so that it is something to give me something that I can look at and think 'Oh, yes, that is what I am going to do'.
- Anne (2714) I have got all my shopping lists there look. Look, loads of them. Look, I kept them from way back, from when I started. And I go back on here more than anything to find out what I want....(2716) I either get the tin or the jar of what I have got left and copy what is on it. (2809) I usually put things down on the calendar.
- Charles (1262) Diary Just odd notes and every day has to have something, like somebody rang. (1299) I try to fill in one entry everyday, even if it is only a note, somebody rang or a letter from somebody else. No day is blank. (1304) I usually put what the classic FM Concert is.

### Planning:

- Charles (1243) I go during the week because the Sunday services are too long for me. They last an hour and a half and my concentration can't take it in (1251) I am okay after that.
- Stan (2937) If you plan your day, morning, afternoon and evening, it does give you a guide as to what you should be doing if you are not doing it.

## **(c) Cognitive Strategies**

### Attempts to recall: (Unspecified techniques)

- Dorothy (771) I would have to start up the names and that...or try at least.
- Rose (1929) Name: I kept thinking all the while and then suddenly it came to me before anybody said it. (1955) you just hope that...it is going to come to you. It does come after a while.
- David (2577) You just try to remember it.
- Margaret (478) If I had mentioned somebody and want to mention them again I do rather try hard to recapture the name of the person.
- Stan (3038) If you couldn't think of something you try to dismiss everything connected with it and suddenly it comes back to you.

### Word Association:

- Donald (974) I only remember your name by sailing, Tracy Edwards.  
Answered 'Yes' re: attempts to link things.

### Self Talk:

Donald (1028) I just try to tell myself not to be stupid (not helpful)

### Retrace Steps:

Donald (957) I try to think what I was doing the day before, so that I would know what the next day is, but I can't remember.

Stan (2898) I find that if I relive or rethink my journey I can sort it out quickly so it doesn't effect me any more than that..... I find that if I go back over it, relive it, I get the proper answer that I should have.... You sort of wind back your brain and go over the ground again and then I find it, but I find that I have to sort of relive these situations and then I am alright.

## **(d) Hopeful Waiting**

Rose (1845) **Lost:** I would just sit in the corner and hope that I get better. (1927) **Name:** I just sat there in this room talking and thinking please someone call her by her name, because I can remember your name and I know that I know it. (1955) You just hope that somebody is going to mention their name.

Anne (2743) **Confusion: time:** I fall asleep in here and I wake up and the television is on and I am looking at it and I think 'I don't recognise that'. And I am looking through there (TV magazine) to see what it is, And I can't find what it is. And um, its either like this [daytime] or it is dark so I just sit here and wait until something turns up on the television and I realise that its late in the evening and I should be getting ready to get to bed...

David (2572) **Names:** Try to keep quiet I think. Yes, I wouldn't like to ask anybody their name, knowing that I had known them for months or years. (2611) Then I just sort of sit around or stand around for a few minutes and it comes back to me. Yes, so I am not daft altogether.

Charles (1213) I think of something to say. Something comes back.

Donald (1026/30) **Confusion re: place** Just wait until I come to.... Everything goes so slowly.

## **3.4.3. NEGATIVE SELF-PERCEPTIONS**

### **(a) Personal attributes**

#### Appearance:

Dorothy (788) I thought I looked so awful. (795) Well, I think I just felt that I am bound not to look the same as gradually it will get worse. (801) I feel that I must look so different. (804) Well I would feel that my face would look.....all kind of loose. (810) I think my clothes look funny or my hair looks funny. Something personal.

#### Confidence:

Dorothy (800) **Socialising:** But I Haven't got the nerve.

Donald (912) I have no confidence in myself at all

Nuisance:

Rose (1703) ..Even now while I am like this and must be a pain in the butt...(1971) Anyone with this will tell you that you are a pain in the butt. (1974) You're just a nuisance.

Not belonging:

Rose (1841) Being lost: Well it is just as if you don't belong

**(b) Intellectual Abilities**

Dorothy (852) Planning: Hopeless

Rose (1916) Forgetting: I feel useless and what an idiot basically. (1655) So your job is pretty hard isn't it?. You have got to support the stupid ones as well as the healthy ones. (1961) Names: Horrible and not coping .....

George (2249) Speech: Silly fool

David (2613) Daft

Charles (1176) It seemed to affect my intelligence because I couldn't pick things up.

**(c) Ageing**

Anne (2710) It just makes me feel as though I am getting old. (2723) I know that I am getting old. (2819) I know that I am getting old because I look at the photo up there and I don't look a bit like that now do I?. I have lost half of my hair. The only thing I have got there that I have now is this kink in my hair here.



### **3.5. Participants' responses to others' reactions to their symptoms of Dementia. (Corresponds with Table 5)**

#### **Part 1: OTHER PEOPLE'S REACTIONS TO THE PARTICIPANTS' SYMPTOMS OF DEMENTIA.**

##### **3.5.1. OTHER'S REACTIONS**

##### **(a) Informing participants' about their symptoms**

- Rose (1511) It is something that you don't really realise until somebody says to you 'Rose, I've just told you that' and you realise that you are repeating yourself. (1521-) Because you really and truly can't remember what people have said before and you find people telling you that you are repeating yourself, 'But Rose, you have just told me that'.
- Anne (2735) If I am talking to my friend and I happen to mention my daughter and she'll say to me 'That's not her name. Who are you talking about?' and then I have to point to the picture up here. (2821) Repeating: She will say 'You have already told me that'. She points it out. She points out lots of things to me.
- David (2474) May picks me up now and again and puts me right.
- Margaret (540) Answered 'Yes' to others informing her of her repetition
- Donald (1008) I told (grandson) about it and later in the afternoon I started telling him again. And he said "You've told me that".
- Stan (3081) I do like to reminded and my wife does that alright.

##### **(b) Externalised Emotional Reactions**

##### **Verbal Aggression:**

- George (2351) It must be that they sort of don't know what is going on inside of me and I think that at times they get, or you get a little bit, um, I'd say a bit shirty.
- Charles (1488) She shouts even louder.....(1489) She is a bit annoyed, yes.
- Margaret (633-6) As I say she shouts which is not the best way of communicating with somebody.....Well now that she had to do so much more for me it has become very much more accentuated. Especially the shouting

##### **Teasing:**

- Charles (1486) I keep saying what and she says 'You, Mr What'. She call me 'Mr Sieve' because I forget things.

##### **Expressions:**

- Rose (1515) And whoever you are talking to, you suddenly see that they are looking at you as if to say 'What the hell are you talking about?' (1618) You answer things, but you don't answer them properly and then I see Harry looking at me, looking...'Bloody hell, what is she going to say next'.

**(c) Assistance**

- Dorothy (839) Well the girls usually when they hear me stuttering and stammering the girls know that that is a signal to try and change over....(844) They are so good about it. (846) The are marvellous about it.
- Rose (2146) Golf: She suggested that I take up painting

**(d) Withdrawal**

- Rose (1544) Neighbour: I mean the lass over the back here she used to come round quite a lot, but I never see her.....She used to bring the children over

**(e) Others' reactions to the participants' counter-responses.**

- Rose (1609) Early withdrawal: My daughter rang me up the next day and said 'Why did you fly off mum? (1612). We went down to Chichester tot he seaside the next day. Why didn't you stay. Cause you could have stayed. We could have managed. (1626) And when I got home I was glad that I was home, but then of course when they ring up and say 'What did you go for?' I missed out again.
- (1630) But surely when you go they must think, 'Oh, Thank God for that'. Well you know, You must speak to tons of people with the same problem.

**3.5.2. PARTICIPANTS' BELIEFS ABOUT OTHERS PEOPLES' REACTIONS TO THEIR SYMPTOMS OF DEMENTIA.**

**(a) Positive Reactions**

- June (99) I think they realise now. (102) I think they are starting to understand. (128) They don't say anything. They understand you see.

**(b) Negative Reactions**

- Dorothy (836) I am sure that I repeat myself until everybody is absolutely....gone to the wall.
- Rose (1921) Harry is absolutely marvelous and must get fed up to the teeth. He doesn't say it, but he must get fed up to the teeth. (1546) Neighbours withdrawal: I know it's because I must embarrass her.
- Stan (3040) Well it must be vary annoying for her when I can't think of something. I go up to her and say "I was going to say something to you and it has slipped my memory for a minute".

**(c) Perceived negative attributions about the participants.**

Dorothy (789) I am sure people expected me to look rather odd. You know, but that probably isn't so.

Rose (1515) ..And whoever you are talking to, you suddenly see that they are looking at you as if to say 'What the hell are you talking about?' (1618) You answer things, but you don't answer them properly and then I see Harry looking at me, looking... 'Bloody hell, what is she going to say next'. (2142) Golf: She didn't say anything, but I could sense that she was thinking 'Golly, what the hell have I taken on?'

(1872) I will probably start saying stupid things and she would think 'Oh blimey, what has happened to her?' And rejection again isn't it. It comes down to rejection and when she'd realised there was something wrong with me, it would be rejections wouldn't it? You know, you would think 'Oh, gosh, I am not going to waste my time on her'.

**Part 2: PARTICIPANTS' COUNTER RESPONSES TO OTHER PEOPLE'S REACTIONS TO THEIR SYMPTOMS OF DEMENTIA.**

**3.5.3. IMMEDIATE REACTIONS**

**(a) Negative Emotions**

Rose (1590) And they did come up and say 'Hello Rose, how are you getting on?', and all the rest of it, but I found it so embarrassing.

(1530) Social Withdrawal: Tearful (1882) Social Withdrawal: Its sad really

(1878) Social Withdrawal: Its selfish I suppose. (1880) Its selfish because there must be people out there who are lonely like me but I just haven't got the confidence to go out and make contact anymore.

(2145) Golf suggestion: Guttled (2147). You can't play golf so get painting woman.

Anne ( 2825) Repeating: Feelings: Sorry. I am sorry that I have had to repeat it. I am sorry for my friend really because, well she is getting used to it now. I mean this sort of thing. Just repeating the same thing over and over.

Margaret (641) I don't like people shouting at me.

Donald (1010) Well it annoys me because I know I shouldn't do it.

Stan (3087) Informed: It makes you get disgruntled.

**Anxieties:**

Rose (1867) Social Withdrawal: I don't know whether it is rejection or whether its...I have never really analysed it. (1877) So that's basically it, it's a fear, a fear of rejection. (1871) Social Withdrawal: I will probably start saying stupid things. (1548) I think, 'Oh, God, she suss out that I am stupid and that I can't cope'

## **(b) Justification of others' reactions**

- Margaret (544) After all you expect to tell people something once & once only. To do anything else is unnecessary and therefore to be avoided.
- (641-4) She thinks she has got to shout at you or you won't hear her and of course she is correct in many ways.
- Rose (1517) Others expressions: That when you begin to think 'Yeah, what's going wrong?' (1621) Husbands perceived withdrawal: I don't know whether he wanted to leave because of me? Quite possibly.

## **(c) Denial**

### Dismissive:

- Rose (1532) Other than that it is fine.

### Displacement:

- Dorothy (842) Changing subjects: Well it's fine really cause they are all pretty well interested in saying things....
- Rose (1610) Questioning of CS: But Harry wanted to come home because he didn't want to drive home in the dark (1620). But he wanted to leave. (1938) But Harry wanted to escape as well as me. So maybe it is something in him as well because he said 'Oh, dear, I want to get home Rose'. So maybe he is beginning to want his space as well. I don't know.
- (1623) But anyway we got home in the sun. It was a lovely evening and a lovely drive. Whereas if you come home in the dark it is as miserable as sin isn't it?
- (1936) We couldn't have stayed. I mean, she only lives in a little town house. Where would we have slept for a start? She would have given up her bed, I know.
- (1943) I felt that it was nicer for the young people to be on their own.....But really it is a feeling that it is time to escape. Perhaps your mum even feels that way if she's with all the family. She thinks 'let the rest of them have time on their own'. Which is just normal isn't it. I mean that's what all families do, I should imagine (1948) It's all to do with age again, but you know as you get older you want the youngsters to have a good time. (1951) But surely that is just old age and I don't know how that can be mixed up with Alzheimer's.

## **(d) Social withdrawal & avoidance**

- Rose (1526) Realisation: That is why I sort of feel that I don't really want to meet people and I don't want to go out and I don't want to make contact with anyone. (1579) but you cut off. Embarrassing: (1591) You just want to cut away. (1613) I just wanted to come home again. Fear of rejection: (1878) It just makes me feel well I just won't bother. (1925) (husband) he must get fed up to the teeth. ...Sometimes I think it might be a good idea if I went away and gave him a break. If I went and stayed with my daughter.

### 3.5.4. MANAGEMENT STRATEGIES

- Dorothy (845) We are thinking at the moment what we can do and what is the best way to handle this and they [the Family] are marvelous about it.
- Anne (2737) Then I have to point to the picture up here and when I look at it I remember her name.
- Charles (1490) I tell her not to shout at me.
- Ignore  
George (2364) .... If people are going to be a bit strange or funny as they sometimes are you just, well, ignore it.
- Stan I try and dismiss it as much as possible. Let it go.
- Apologise  
Anne (2822) Repetitiveness: I say, Oh I'm sorry
- Admit  
June (127) I said 'I forgot'

### 3.5.5. PARTICIPANTS' SELF - PERCEPTIONS

#### (a) Negative Personal Attributes

##### Confidence:

- Rose (1857) Now really, I should nip down and see her....But I can't and I keep putting it off and off and off and thinking 'Yes, I must go and see her', but I never do. I haven't got the nerve to go and knock on that door and so my confidence has gone. (1863) I wouldn't dare go down there on my own.....(1870) I think its because I think I haven't got the confidence in myself.

##### Nuisance:

- Rose (1616) I just feel that I am a pain in the arse to be honest. You know.....You think 'Oh, Dear.'. You answer things, but you don't answer them properly.

##### Not belonging:

- Rose (1580) Social Withdrawal: You don't feel that you belong. (1723) Don't belong I don't know....just a complete lack of confidence. Your not sure that anything you say is going to be really of any interest to anyone.....Wherever we go I do tend to sit back and list now because I don't have the confidence to join in with the conversation which is crazy really....You know I might say something stupid or they will look at me and say 'What are you talking about'. (1880) Its selfish because there must be people out there who are lonely like me but I just haven't got the confidence to go out and make contact anymore.

**(b) Negative Intellectual Abilities:**

Rose (1581) **Social Withdrawal:** You just think, 'I'm stupid', let me get out of here'. (1595) ....But if you've got it you don't think like that. You think, 'Oh my God, what an idiot I am'. Let them get away.

Margaret (541) **Notification:** I just realise that I am stupid. One doesn't want to be stupid.

Donald (1011) It just shows that I am a bit more stupid

**(c) Loss of Skills**

Rose (2150) **Golf:** It made me feel that I had lost another skill. Lost another friend and that I was on my own again. (1519) You just lost control in a way

**3.6. Participants responses to the cessation of activities as a consequence of dementia.**  
(Corresponds with table 6)

**3.6.1. PARTICIPANTS' RECOGNITION OF THE DEMISE OF SOCIAL INTERACTIONS, HOBBIES AND INTERESTS AS A CONSEQUENCE OF DEMENTIA.**

**The effect of the symptoms of dementia on socialising/interacting with others generally.**

- Dorothy (786) It's funny it has stopped me from meeting ever so many people. And going... particularly at Christmas time when there were parties I didn't want to go because I thought that I looked so awful. (801) I feel that I must look so different so I haven't gone.
- Margaret (524) I realize that I find great difficulty in getting to know people. Much more difficulty than in the past because one cant remember anything even if you capture some impression you cant remember it you see. The memory deficiency is operating all the time, in everything one does.
- Donald (907) I go to the day center. I cant talk to them because I forget what I said to them the time before.

**Specific Hobbies & Interests**

**Letter Writing**

- Dorothy (724/33) ...then I suddenly discovered before Christmas that I couldn't ...wasn't writing I rather used to pride myself on letters. (747) He [husband] used to leave most of the letters and writing to me.

**Theatre**

- Dorothy (805) (Husband) loves going to the theatre. Its his greatest joy and I still can't bring myself to go in the evenings (Physical appearance)

**Leaving the building**

- Margaret (613) Do you realise I haven't been out of this...physically out of the....I have scarcely been out of this building since I have come here and I have been here quite a while now.

**Mending**

- Donald (930) I'm an engineer by trade and I was always making things and doing things with my hands and I can't do anything now. (936-939) Well I would always repair anything that went wrong. If I take anything to pieces now it goes more wrong.....Partially because I forget. (1074) I had a very nice workshop outside with machinery in it, which all had to be taken down.

### Walking

Stan (3029) Well it's country walking. We don't do that now. When we were younger and we had good feet for walking we used to like to go to [name of park] and places like that.

### Church

Stan (3056) We both attend church and are active in it, or have been. We are too old now.

### Activities with significant family members

Donald (1057-60) **Driving** We always liked going away for long weekends.....We used to take the grandchildren down there for a few days on their half term and that sort of thing. ...Just go out in the car just for a run.. ...(1125) We have a caravan. We used to go down there more when I could drive. I used to drive down there a lot. (1126) Driving had an impact on everything

Donald (1063/5) **Driving:** Taking my grandsons out and about which I used to enjoy. Taking them swimming, football, cricket.....Occasionally I go with their mother when she is doing it.

Stan (3060) I can't be active with the boys as I used to. I can't play football or cricket, or any of those things now and sport generally.

## 3.6.1.1. EMOTIONAL REACTIONS

### (a) Positive

#### Relief

Dorothy (812/821) **Theatre:** In a ways it's a relief.....that I haven't got to worry....  
..Feeling that nobody will be coming to go out and meet me or anything like that.

Stan (3061) **Activities with the boys:** It hasn't taken my interest away from it. I am still very interested in tennis, Wimbledon and all the time I find it very interesting, very entertaining.

### (b) Negative

#### Restrictive

Margaret (615) It is very limiting. (617) Which is very serious really because that is my main outlet.

#### Loss

Rose (2113) **Golf:** I do miss it. I do miss it a lot

Donald (1054) I very much miss driving

Donald (1075) **Workshop:** I miss that terribly, but I couldn't use it properly because I couldn't this (arm) and that's why it has been taken down.

#### Painful

Donald (1066) **Activities with grandchildren:** It hurts no end.

Stan (3058) **Church:** It is difficult, hard to accept sometimes if you have got to lay things aside or stop doing it. Its difficult sometimes to give up things.



### Awfulness & disappointment

- Dorothy (750/1) **Husband taking role:** Its awful, its such a shame. I hate it really. Knowing that he will have got things ready and that.
- Dorothy (752) Very kind of disappointed, depressed.....It is so much more interesting if you have got the information to give other people as I always had in the past. (815) **Theatre:** but it is such a shame because it means that I have missed so many shows ....

### **(c) Not meeting others needs**

#### Empathy with other

- Dorothy (809) **Theatre:** Which is rotten for (husband). (823-5)It is very bad luck for (husband)...Just the fact that I can't go with him to the theatre. Be with him at the same time.
- Dorothy (725) **Writing** [husband] practically did all the letters, such a lot to do (tutted)

#### Concern about others abilities

- Dorothy 755 **Writing:** He [husband] isn't probably terribly good

## **3.6.1.2 SELF-PERCEPTIONS**

### **(a) Positive**

- Stan But we work alright with the younger people. They respect us.

### **(b) Negative**

- Donald (1073) Get in the way
- Stan (3056) We are too old how. I am beginning to realise that I am of the past generation and it is a bit old fashioned and slow.

### 3.6.2. PARTICIPANTS' RECOGNITION OF THE DEMISE OF THEIR CHORES AND DUTIES.

#### Domestic etc

Margaret (627) (Name) has taken on more & more all the time. She has taken in so much you see.

Donald (1056/61) Driving: Colossal ....Going shopping. Going to the doctor. We have to get taxis

#### Business/Household Management

Donald (988) bills etc. (Wife) or son. If she doesn't want to do it she gives it to him.

Margaret (686) He does all my business. He goes through all my affairs for me....(No reactions etc),

Anne (28847) She does all the phoning for me. More since I had the stroke. I couldn't pick the phone up and get the number and that already. (I mean when I get any letters now I stick them in the front here and when J comes in she say 'I see you have plenty of letters for me.

#### Assisting others

Rose (1897) I used to drive her everywhere, to all her meetings.

### 3.6.2.1. EMOTIONAL REACTIONS

#### (a) Positive Emotions

Margaret (577) I am very pleased to accept her help. (578) I am only too glad to give them up. (579) I don't want more than I have to do.

Anne (2854) Well it is a relief really, to know that I have got someone to do it for me.

#### (b) Positive emotions regarding others

Donald (992) I've always relied upon him (son) for help. I trust him completely. (997) I just trust her (wife). If it goes wrong (son) will get us out of trouble.

#### (c) Negative emotions regarding others

Donald (995) I just hope she (wife) understands what she is doing.

### **3.6.2.2.**

### **NEGATIVE SELF-PERCEPTIONS**

Rose (1898) Well I can't drive, so maybe I wouldn't be much use to Claire.

Margaret (613) I am not capable of shopping.

Donald (1105) Decision Making I would like to do it again, but I'm not capable. As far as I can see I never will be.

### A summary of the research diary

#### May 1998

I have been on my older adult placement now for two months. It has struck me that in comparison to child and adult services, the ethos and structure of this service seems to be largely guided by the medical model of care. I have participated in a number of clinical review meetings for people with dementia. The predominantly biomedical focus prompted curiosity about the social and psychological needs of this population. I conducted a literature search pertaining to the subjective experiences of people with dementia and was surprised by the scant results. As there seems to be clearly a void in the research, I am considering the possibility of investigating the subjective experiences of dementia for my research dissertation. The research literature suggests that one impact of chronic illness was the disruption to person's sense of self (Charmaz, 1983). I wondered if this was true also for people with dementia. I hypothesise that a relationship exists between negative self-perceptions and low self-esteem in dementia. I remain curious as to why such research has not appropriately been undertaken.

#### June 1998

Qualitative methodology was considered the most appropriate for investigating a phenomenon about which little is known. Grounded theory methodology and IPA are being considered. To develop my research questions and methodology I have begun to explore the social psychological models of self and identity. In particular, I have read the social constructionist theory and Breakwell's (1986) writings on 'Threatened identities'. These have been extremely helpful in shaping my initial ideas. I have however, remained mindful of the influence exerted by the existing literature on the direction of my research. I initially developed three research questions, which drew upon Breakwell's ideas of the content and value dimensions of identity. However, I realised that before I could explore these concepts I needed to investigate the participants' awareness of their illness. Two further questions were therefore added. It really feels as though the research methodology is coming together and am feeling quite excited about the prospect of undertaking the research. A further development is that Sue Holtum has agreed to supervise my research. I have discussed my research ideas with psychologists and trainees. Several people have expressed their opinion that the research topic is both very interesting and clinically beneficial. Their comments were both encouraging and motivating.

#### October 1998

I am relieved that my research proposal has been passed by the exam board and excited that I can proceed. Developing the methodology and procedures for this research has felt like an ethical minefield. Several hours have been spent deliberating over many of the issues, which have emerged. I was therefore pleased and relieved when Steven Boddington, Older Adult Psychologist agreed to co-supervise my research. In particular, I was hoping to obtain support and advice, regarding ethical issues, the most appropriate assessment tools, considerations for interviewing people with dementia and the clinical implications of the research.

#### November 1998

The lead psychiatrist from service one provided permission for me to undertake the research with the service. The procedure for recruiting participants was clarified so that I could complete and submit the application for ethical approval.

#### December 1998

I was pleased to receive ethical approval to conduct my research in service one. With this approval I am confident about completing the research in sufficient time. I have made arrangement to meet with mental health workers in January to discuss the inclusion criteria and to identify potential participants from their individual caseloads.

#### January 1999

Meeting keyworkers has proved to be very difficult. My combined travelling time to and from service one is approximately three hours which is very time consuming for each study day. It was bewildering when keyworkers did not kept their appointments with me and this has taken up a lot of time. Furthermore, when two or more people are involved with the same client it is often not possible to meet them on the same day. Despite these frustrations a significant number of people have been proposed. Interestingly, the views of keyworkers differed considerably, regarding the involvement of people with dementia in research. Some keyworkers readily identified potential participants while others felt that people with dementia were unaware of their dementia and did not feel that they could talk about their experiences.

#### February 1999

I was surprised to discover that many of the people proposed for the research over the past two months did not meet the inclusion criteria. Some had been assessed with 'severe' dementia, others had additional mental health problem or their first language was not English. The recruitment process has also become increasingly complicated. For example, differing assessment tools have been used for measuring the presence and severity of dementia. For some, these assessments have not been undertaken for several months, and so their current mental status is unknown.

#### March 1999

I discussed my anxieties with Steven Boddington. As the MMSE has often not been conducted within the previous three months it was decided that I should administer this assessment tool. I felt that it would be advantageous to extend the sessions from one to two, to separate the assessment procedures from the interview and to take account of attention and fatigue. I have therefore requested approval from the chair of the local research ethics committee for these amendments.

#### April 1999

Although extremely necessary, the procedures undertaken to address all the ethical issues and inclusion criteria ie., meeting with keyworkers, consulting medical files for each person, and distributing keyworker questionnaires has proved to be a much lengthier process than was imagined. It was important to obtain written confirmation of whether participants meet the inclusion criteria as verbal and written reports sometimes differed. However, in some cases, I have had to wait several weeks for the return of the questionnaire, which has prevented me from proceeding with research. I have spent a considerable amount of time contacting keyworkers to request their return. On their return, I have been surprised by the information provided. Although keyworkers were informed of the inclusion criteria prior to identifying potential participants, a large number have been removed from the research, as they do not meet these criteria. Some were unable to provide consent or participate in an interview and most surprising a few had not even been diagnosed with dementia.

Furthermore, it emerged that differing clinical practices were in operation as to whether a diagnosis of dementia was disclosed to service users and their carers. The actual information provided to service users and their carers was not routinely documented in medical files and mental health workers were often unable to provide clarity. It seemed that despite dementia being

diagnosed, service users were often told that they had 'memory problems'. This has made the recruitment process both confusing and frustrating. Difficulty obtaining clarity has raised my concerns about unintentionally contacting people who have not been informed of their diagnosis of dementia. At this stage I have only seven potential participants to contact which is extremely disappointing and concerning.

#### May 1999

I am very concerned that it is now the beginning of May and I have been unable to recruit participants to the study. It seems that I will not be able to meet the July submission date for the research. I am extremely upset, disappointed and frustrated about the potential need to defer my submission until March 2000. In addition to not obtaining my qualification and graduating with my year group, this decision has significant financial and personal implications.

I was relieved and excited to receive my first participant consent form. I have had no further responses from the carers or family members contacted. I have begun to make inquiries about extending my research to a second service to maximise my opportunity of recruiting participants. It is difficult to contemplate beginning the lengthy recruitment procedure again in a second service, especially as the outcome was extremely disappointing. I hope that the outcome will be significantly improved.

#### June 1999

I initially stipulated that I wanted to recruit only those people who had actually been informed that they had 'dementia' to avoid disguising the nature of the study. However, due to the difficulties encountered with recruitment, I was advised to include both those who had been informed of their full diagnosis and those who were provided with an alternative terminology. I was also advised to use the blanket term of 'memory problems' on all correspondence to prevent any unplanned disclosure of the diagnosis. I agreed with the advice, as this issue was clearly preventing people with dementia from participating in the research. I have written to the local research ethics committee requesting chair approval for the amendments and have included this procedure in my application for ethical approval to conduct the research in service two. I have completed the pilot interview. The vagueness of the open questions caused some difficulty for the participant. This highlighted the need to include a series of prompts that can be introduced if the participants have difficulty answering the open questions.

#### July 1999

I met with a clinical psychologist who has experience of interviewing people with dementia to gain advice about the prompts that should be included into the interview schedule. I felt that this was a very productive meeting and I feel confident that these amendments have improved the interview schedule by making it more accessible to the participants. I received ethical approval to conduct my research in service two and a second consent form from a participant in service one.

#### September 1999

Service two comprises of five teams and I have therefore spent a considerable amount of time presenting my research at team meetings and meeting individual mental health workers. However, despite my efforts no potential participants have been identified so far. I have also been permitted access to a dementia case register, which could be another means of recruiting potential participants. I also plan to extend the research further to a third service. This service consists of three community mental health teams for older adults. The ethics committee for service two also covers these three teams and therefore only chair approval will be needed.

### October 1999

The training course finished on the 30<sup>th</sup> September 1999. I was very disappointed not to have completed the course with my year group and I perceive that there is still an uphill struggle ahead in order to recruit the participants. During the month of October I took a break from employment to concentrate on recruiting participants. Much of the month was spent sifting through the information on the dementia case register. As much of the information was not up-to-date I also needed to consult the medical files. It came to my attention that many of the people identified were no longer in contact with the mental health services, which is important for the research and it was unclear whether the details on file were current or outdated. As all of the people identified on the dementia case register had agreed to participate in research I am hopeful that this may be a successful means of recruiting participants. I also continued to meet with mental health workers to identify potential participants on their individual caseloads. Eighteen people were initially identified from the psychologist's caseload from service 3 and after consulting the medical files six were removed and the psychologist was asked to complete keyworker questionnaires on the remaining twelve.

I conducted the first interview 'proper' following amendments to the interview schedule. I was pleasantly surprised by the lengthy and detailed accounts that were provided. The participant was very welcoming and seemed genuinely pleased to talk about her experiences. She was articulate, insightful into her symptoms of dementia and was clearly able to describe her experiences. The participant's awareness and level of engagement in the interview does not support the existing literature. For example, Goldsmith (1996) reported on the perception that people are unaware of their dementia and that communication and expression are rarely possible. I am excited about undertaking further interview and I am very curious about whether I will obtain participants will demonstrate similar levels of awareness and engagement and talk about similar experiences. At the end of the month I felt very despondent, as I had worked continuously but had not been able to organise or conduct further interviews. I will need to wait for the outcome of the numerous meeting I attended.

### November 1999

At the end of the month of October I felt extremely exhausted. I took my two week holiday in a year to recharge my batteries before starting my job and I am aware that working and attempting to complete the dissertation is going to be extremely taxing especially as the hoped for results were not obtained during the month of October. I was extremely pleased to be contacted by the psychologist for service three who informed me that he had identified six potential participants and attempted to personally contact each of them. Four had agreed to participate in the research but are unable to meet me until the New Year. I am feeling extremely anxious again about being able to complete the research by the submission date.

### January 2000

I conducted interviews with two people from service three and one from service one. All participants provided substantial information, were articulate and able to talk about their experiences of dementia. I have thoroughly enjoyed undertaking the research interviews, possibly more so as I have waited so long to obtain the data. Two participants from service three were withdrawn from the study by their partners' felt the interview would be too demanding and that there were too many people involved in their care. Sadly, given the continuing problems with recruitment I needed to request a further deferment to the submission of my research dissertation. I feel very despondent at present and can not see the light at the end of the tunnel.

### February 2000

In the light of the deferment I have decided to extend my recruitment remit further, to a fourth service. However, given the history of this research I am not confident that recruitment will be any easier from this service. It also now feels overwhelming at times to be liaising with four different services which comprise a total of eleven teams and one case register, especially when I have limited time to contact people.

### March 2000

I obtained ethical approval to contact people on the dementia case register despite their ceased involvement with the mental health services. I sent letters to potential participants and their carers to maximise their chances of receiving the information. I was unable to obtain the current addresses for many of the participants or their carers. I also obtained ethical approval to conduct my research in service four. A third participant from service three was withdrawn by his partner. The third and final participant cannot be interviewed until he returns from holiday in May, which is nearing the submission date.

Data Analysis: I have transcribed all of the interviews to date and have begun to analyse the data using Interpretative Phenomenological Analysis (Smith, 1996). Very clear categories have begun to emerge, such as 'negative self-concept' which include themes such as feeling 'stupid'.

### April 2000

I met with the Psychologist from service four. Three potential participants were identified. The Psychologist had personally contacted them to discuss the research and all had consented to participate in the research. I contacted all three and made time to visit them to conduct the research. This was the quickest recruitment throughout the history of the research.

### May & June 2000

I have completed the three interviews from service four. I also interviewed a participant from the dementia case register. I remain impressed by the content of the interviews and the extensive amount of information provided. In addition to talking about their current experiences I have been surprised by the extent to which people are considering the future with respect to themselves and their partners. I have followed up the letters to participants from the register with phone calls, but in the majority of cases have been informed that the person no longer lives at the address given. I have taken six weeks leave from work, starting from the last week in May to concentrate on analysing the data and writing my dissertation. The time frame is extremely tight.

Data Analysis: During my supervision with Sue Holttum we discussed how the researcher attempts to adopt a neutral stance to refrain from imposing their view of the world during data analysis. A themes and categories emerged from the data I became aware that the labels I was using were influenced by my own frame of reference. For example, I began to develop categories which correspond to Lazarus and Folkman's (1984) model of coping and Freud's (1926) defence mechanisms e.g., denial. During our discussion, I recognised that the coping model had become too influential in my analysis. I therefore returned to the data, allowed the themes to emerge from the data and resisted imposing pre-existing theories upon the data. I acknowledged that my frame of reference would influence the category headings and content to some degree, to allow for the development of meaning from the data. Furthermore, on occasions our codings of the data differed. For example, there was some discrepancy about whether responses reflected a participant's acceptance of their illness or they were denying the impact. I questioned the extent to which I was imposing interpretation on the data. Following discussions with my supervisors the codings were either re-labeled or two codes were combined in one categories and the heading altered accordingly.



Three key areas emerged from the data. These are 1) the participants' reactions to their recognised symptoms of dementia. 2) other people's responses to the participants' symptoms of dementia and the participants' counter-responses, and 3) participants' reactions to the loss of activities as a result of dementia. Insights into the individual's self-perceptions in relation to these three areas also emerged. I am extremely pleased by the outcome of the data. The clarity of the data has provided me with a lot of insight into these participants subjective worlds.

#### July 2000

I met with two of the participants to obtain their opinions regarding the themes and categories which emerged from the data and the extent to which these reflected their experiences. Both demonstrated a high level of agreement. Participant six however, stated clearly when disparity emerged. She reported that the interview was a positive experience. She experienced the similarities and differences in experiences as interesting and felt that it made her feel less alone with illness and different. 'She was curious about and compared her 'management strategies' with the other themes that had emerged. She reported that she considered other people's strategies to be productive and this produced feelings of hope regarding her own means of coping.